



Section I: Overarching Issues

Chapter 1: Access and Resources

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SECTION I: OVERARCHING ISSUES

The Overarching Workgroup was formed to focus on cancer control issues that bridge across all cancer types. Healthy New Jersey 2010 provides a systematic approach to monitoring and tracking health promotion and disease prevention objectives by targeting overall health status, access to health care, fundamentals of good health, preventing and reducing disease, and strengthening public health capacity. The Overarching Workgroup used this paradigm in regard to comprehensive cancer control by designated five subcommittees: Access and Resources (Chapter 1), Advocacy (Chapter 2), Palliation (Chapter 3), Nutrition and Physical Activity (Chapter 4), and Childhood Cancer (Chapter 5).

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CHAPTER 1. Access and Resources

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ACCESS AND RESOURCES

IMPORTANCE OF ACCESS AND RESOURCES FOR CANCER PREVENTION AND CONTROL

Advances in cancer research, education, outreach, screening, surveillance, and treatment are only effective if the public has proper access to healthcare that offers these benefits. As defined by the Institute of Medicine, *appropriate access to healthcare* is “the timely use of personal health services to achieve the best possible outcomes” (1). The Access and Resources Subcommittee of the Overarching Issues Workgroup was formed to develop strategies for increasing resources and physical access to cancer care for New Jersey residents, and the findings of this subcommittee are presented below.

In 1998, 33 million U.S. adults aged 18 to 64 years lacked health insurance (2). Individuals without routine access to primary healthcare do not receive timely care, such as cancer screenings to detect the onset of disease. Without access to proper healthcare, these individuals are more likely to be diagnosed at a later stage of cancer and more likely to experience higher morbidity and mortality. Individuals with insufficient resources and less than optimal access to healthcare tend to belong to ethnic minority groups, are unemployed, and have lower levels of education and income, generally below the poverty line (3). Barriers limiting access to appropriate healthcare can be cultural, systemic, personal, or societal in nature. Determining the unmet needs of underserved populations in the state, as well as the barriers they face in obtaining healthcare, may aid efforts to improve access to cancer care for all New Jerseyans (2).

Low rates of minority participation in cancer screening programs have prompted a number

of initiatives over the past decade, at both national and local levels. While these efforts have begun to narrow the screening gaps between some groups, significant disparities persist (4). Nor is coverage by managed care sufficient to ensure equivalent screening across all income groups. In a recent study analyzing the relationship between household income and mammography utilization in a managed care population, it was found that, even within that population, as income increased, the rate of mammography use increased (5).

Several studies describe proven techniques to increase access to cancer care. By offering mammograms through community-based influenza clinics, researchers found that the bundling of services is a viable means to exploit available interventions to improve health (6). A study conducted in Rhode Island increased accessibility of screening mammographies by reducing cost and implementing a telephone appointment and tracking system (7). Additionally, interventions aimed at increasing participation in health programs should focus on non-economic aspects of access, such as help-seeking behaviors and perceptions of access to care (8).

ACCESS AND RESOURCES IN NEW JERSEY

Despite public and privately funded programs initiated in the past decade to begin addressing cancer-screening needs for New Jersey’s indigent populations, access issues persist. (See Appendix E for information on efforts by New Jersey’s breast and cervical cancer program to increase access to screening services for underserved populations.) It is paramount that public and professional education efforts to increase access and reduce barriers to cancer

prevention, detection, and treatment be addressed via sound strategic planning.

In 2001, an extensive report detailing access to primary care in New Jersey was published by the Health Research and Educational Trust of New Jersey (3). This report detailed geographic variation in hospitalizations for ambulatory care-sensitive conditions in 1995 and 1997. Of the 14 initiatives outlined in this

report, the Access and Resources Subcommittee chose to focus on four education initiatives that speak to comprehensive cancer control. Additionally, the Access and Resources Subcommittee has adopted three evidence-based tactics proposed by the Oncology Roundtable in 2001: community needs analyses, multimedia outreach campaigns, and education of professionals (4).

The recommendations of the Access and Resources Subcommittee are summarized below for the following four topic areas in priority order:

- Identification of Need
- Public Awareness
- Transportation
- Education for the Public and Professionals

GOALS, OBJECTIVES AND STRATEGIES

Overall Goal: To assure that the people of New Jersey have increased access to high-quality cancer prevention, education, detection, and treatment services, including research studies, and to provide sufficient resources to meet these needs.

IDENTIFICATION OF NEED

While the overall picture of cancer among New Jersey residents is encouraging, there is need for similar improvement among a number of population subgroups. As presented in the introductory section “Cancer Burden in New Jersey,” statistics from the New Jersey State Cancer Registry clearly show disparities in cancer incidence and mortality for race, age, geographic location, and gender, among other variables (9;10).

A recently published analysis of the literature by Bach et al, concerning survival of blacks and whites after a cancer diagnosis indicated only modest cancer-specific survival differences for blacks and whites treated comparably for similar stage cancer (11). Researchers concluded that differences in treatment, stage at presentation, and mortality from other diseases should represent the primary targets of research and interventions designed to reduce disparities in cancer outcomes. Although racial differences did remain in the analysis for Bach et al, as well (11), aspects of process of care may also account for at least some of that residual (12). Similarly, a recent study of racial differences in the treatment of early-stage lung cancer suggests that the lower survival rate among black patients with early-stage, non-small-cell lung cancer, as compared with white patients, is largely explained by the lower rate of surgical treatment among blacks (13). Thus, it was concluded by the authors that increasing the rate of surgical treatment for black patients appears to be a promising

means of improving survival in this group. Other research has led to similar recommendations for improving access to diagnosis, treatment, and removal of barriers.

Although some data have been compiled stratifying for each type of cancer the incidence, prevalence, treatment access, mortality, etc., by age, race, gender, and geographic location, these data are largely incomplete (14). Existing data do not permit all factors to be simultaneously assessed, and summary measures frequently hide vast disparities within subgroups, which may be amenable to intervention and improvement. What is needed are studies to develop a more comprehensive database, as well as analytic work targeting those subgroups offering the greatest chances for improvements. Such efforts will help guide the cost-effective deployment of targeted resources toward those areas in need. Also necessary are studies that help define innovative ways to overcome current access barriers. Statistics reported on health indicators should be stratified by a variety of factors. Among women, for example, all age groups do not benefit equally from mammography or cervical cytology screening. Furthermore, population access apparently varies dramatically in different parts of the state. Detailed data are required to identify those in greatest need of services. Resources are necessary to then provide those services. The goal immediately below addresses identification of need, whereas the remaining goals in this chapter involve means to meet that need more effectively by improving access.

GOAL AC-1:

To improve access to cancer-related care and resources in New Jersey, especially for those at high risk and populations in need.

Objective AC-1.1:

To identify relevant ethnic and geographic disparities in access to cancer prevention, education, diagnostic, or treatment services that exist in any age-gender subgroup, including populations with special needs, e.g., physically and/or mentally challenged individuals.

Strategies:

- (AC-1.1.1) Review the literature and New Jersey data to identify disparities in cancer burden across populations.
- (AC-1.1.2) Design and perform studies to explore why disparities in cancer burden exist.
- (AC-1.1.3) Develop a communication plan to disseminate the results of the cancer burden study.

Objective AC-1.2:

To develop solutions to alleviate disparities and gaps in access to cancer-related care.

Strategies:

- (AC-1.2.1) Perform literature review to identify existing strategies to improve access to cancer care and assess evidence of effectiveness.
- (AC-1.2.2) Assess barriers to cancer care that are causing programs to be ineffective, such as unavailability of appointment times or language barriers.
- (AC-1.2.3) Refine *existing programs* designed to alleviate disparities in cancer burden.
- (AC-1.2.4) Develop *new strategies* where needed that address any existing gaps in these strategies to improve access to cancer care among any age-gender subgroup; including populations with special needs.

PUBLIC AWARENESS THROUGH COMMUNICATION

As recommended by the Oncology Roundtable (4), the Access and Resources Subcommittee chose communication through multimedia as the second priority.

Communication techniques encompass three categories: (1) *publicity* or the use of mass media that includes television, magazines, newspapers, radio and/or internet sources; (2) *face-to-face communication* that brings together spokesperson or targeted audience with media personnel who reach those aforementioned audiences via press conference, seminar participation, panel discussion, and/or distance learning; and (3) *controlled communication* or activities that include brochures, booklets, films, and/or internet format.

Some factors that affect the acceptance of public health messages include:

- *Health risk* is an intangible concept.
- People respond to easy solutions, e.g., blood test for cholesterol level as opposed to quitting smoking to reduce cancer risk.
- People want concrete information in order to make decisions.
- Information should not be fear-inducing.
- The public doubts the truth of science.
- Health information may not be a priority issue for an individual.
- People do not feel that a serious illness can strike them.
- The public can hold contradictory beliefs. People may believe, on the one hand, that an illness cannot strike them, while also believing that everything can cause cancer, and thus one cannot avoid it.
- People live for the present and tend not to worry about the future.
- The public does not understand science (15).

The design of a health message may convey facts, alter attitudes, change behavior, and/or encourage participation in decision-making. Generally these purposes overlap and are progressive. “That is, for persuasion to work, the public must first receive information, then understand it, believe it, agree with it and then act upon it.” Messages need to be developed with an eye to the desired outcome. Messages should be clear in order to assure understanding and limit the possibility of misunderstanding or inappropriate action. There should be consistency in the health messages disseminated by government, health institutions, industry, non-profit agencies, and public interest groups. The main points should be stressed and repeated. The spokesperson and source of the information should embody credibility. These factors play a pivotal role in acceptance of a health message (15).

New Jersey has experienced some successes in communication. REACH 2010 developed a community action plan through its 33-member organization, Community Coalition. The success of REACH 2010 was due to this action plan and a very involved coalition.

The Access to Primary Care in New Jersey Report (3) recommended development of a comprehensive directory, culturally appropriate patient education classes, and diverse educational materials, as well as provision of cultural competency training for healthcare professionals. Overall, the health message should be based on what the target audience perceives as relevant for them (15). The Access and Resources Subcommittee recommends the goal, objective, and strategies below relating to public awareness through communication.

GOAL AC-2:

To promote public awareness of cancer prevention, detection, and treatment services in New Jersey.

Objective AC-2.1:

To identify and enhance communication methods among all organizations with an interest in cancer prevention, education, detection and treatment services, including research studies.

Strategies:

- (AC-2.1.1) Organize a media campaign to highlight the cancer needs in New Jersey (as identified in the Identification of Need section of this chapter), available cancer-related community services, and programs addressing gaps in care.
- (AC-2.1.2) Enhance the cancer resource guide for New Jersey – to be able to locate doctors.
- (AC-2.1.3) Identify/develop logo/symbol for cancer awareness.
- (AC-2.1.4) Assess the extent of the increase of cancer awareness in the public and which strategies are linked to that increase.
- (AC-2.1.5) Encourage public-private partnerships to expand cancer health communication efforts.
- (AC-2.1.6) Promote collaboration with traditional and nontraditional partners to improve communication about access and resources for cancer education, detection, and prevention services, including research studies.
- (AC-2.1.7) Disseminate information about New Jersey Cancer Education and Early Detection Program (NJCEED) services and sites. (See Appendix E)

TRANSPORTATION

The complex issue of healthcare access includes many barriers, including a lack of efficient and affordable transportation. According to a report by the New Jersey Department of Health and Senior Services,

“Physicians and clinics may not be located in places which are easily accessible, particularly to people who lack private transportation” (16). In a study of access to primary care in New Jersey, Vali notes, “Transportation options are often limited for people living in rural settings, seniors, and

those with disabilities and diseases. Some options provide only one-way transportation, and cab fare is viewed as prohibitively expensive” (3).

Vali’s report on access to primary care in New Jersey (3) includes a summary of barriers by type and notes that one system-related barrier is “limited public transportation routes and options.” In metropolitan areas, which offer more extensive public transportation systems, schedules and route maps can be confusing to consumers with limited knowledge of such systems. Furthermore, schedules and route maps may not be widely available to the general public.

The experience of the Bergen County Cancer Education and Early Detection Program (BCCEED) demonstrates of the importance of including transportation support in designing health programs for the underserved. BCCEED provides opportunities for women and men living in Bergen County to undergo free cancer screenings, if they meet program guidelines concerning age, residency, insurance, and income. The program is designed to provide access to breast, cervical, colorectal, and prostate screenings to clients from underserved populations. Although lack of insurance and prohibitive costs are the primary reasons cited by this population for low screening rates, BCCEED identified another significant barrier as lack of transportation. While the CEED program offers access to screening and diagnostic appointments, and in some cases free access to cancer treatment, the program is unable to provide transportation to program participants.

During the course of a year, nearly 27% of BCCEED clients require transportation assistance to screening and medical appointments funded by the CEED program. Past efforts to utilize existing community transportation resources resulted in frequently missed

appointments due to inefficiencies within the system. Missed appointments, valued at \$200.00 each, were frustrating for both clients and CEED program staff. In January 2001, a grant was received from the Susan G. Komen Breast Cancer Foundation to provide door-to-door taxi service for women requiring this service. As a result, only 3% of clients have missed appointments this year due to transportation-related problems, and no one has missed an appointment due to transportation problems since March 2001.

The American Cancer Society (ACS) offers free transportation services to patients undergoing cancer treatment. This program, staffed by volunteers, provides patients with transportation to radiation or other medical appointments during the treatment phase. A victim of its own success, the program’s demand for transportation outstrips the number of ACS volunteers available to provide this important service. To estimate the costs of transportation, the American Cancer Society expenditures for transportation were calculated. In Fiscal Year 1998, ACS provided the following cancer-related transportation services in New Jersey: 473 volunteers transported 1,072 patients to treatment centers representing 11,358 trips. This volunteer service had an estimated dollar value of \$533,772. Approximately 250 patients received direct financial assistance for their transportation in the amount of \$83,688, total.[^]

With a population of nearly 900,000 residents, Bergen County (mentioned above in connection with the BCCEED program) offers a limited number of bus routes across the county. For New Jersey residents living in less urban areas, bus service is even more fragmented. Lack of centralized, efficient public transportation forces vulnerable

[^] Calculated by American Cancer Society, Eastern Division Internal Documents, 1998.

populations to rely on community resources to meet transportation needs. However, as illustrated, the private sector is often overwhelmed and unable to keep pace with demand.

Although recognizing these as only a beginning, the Access and Resources Subcommittee offers the goal, objective, and strategies below as means to improve transportation services for cancer care in New Jersey.

GOAL AC-3:

To improve transportation in order to increase access to cancer care in New Jersey.

Objective AC-3.1:

To identify obstacles to adequate transportation for cancer-related services encompassing education, screenings, and treatment.

Strategies:

- (AC-3.1.1) Identify those counties that currently have successful area-wide transportation (AWT) van services to explore best practices.
- (AC-3.1.2) Identify communications deficiencies within the AWT system.
- (AC-3.1.3) Provide incentives to support low-cost transportation for those in need of cancer services, e.g., by investigating a state tax credit and/or arrangements with private foundations to support provision of low-cost transportation.
- (AC-3.1.4) Explore provision of public transportation vouchers to those in need of cancer services.
- (AC-3.1.5) Support the American Cancer Society's efforts to make transportation services more widely available to cancer patients.
- (AC-3.1.6) Identify principal agency and centralize transportation services for cancer patients.
- (AC-3.1.7) Explore opportunities to provide transportation for cancer patients via faith-based communities, assisted living facilities, and community transportation, e.g., "Assist-a-Ride".

EDUCATION FOR THE PUBLIC AND PROFESSIONALS

The Access and Resources Subcommittee determined that both the public and professionals have a general lack of cancer awareness, especially in regard to cancer screening. A review of the New Jersey public education curriculum revealed that little health prevention and promotion is being taught to children in younger grades. The textbooks currently being used for high school, although more extensive, lack comprehensive information about cancer prevention, risk factors, and early detection. Additionally, the critical shortage of nurses in New Jersey directly impacts all aspects of cancer care and control.

The goal of health education is to impart the necessary knowledge, attitudes, and skills required to effect positive change in an individual's behavior. Public education plays a vital role in disease prevention and health promotion. Health education programs designed to promote changes in health behaviors and to encourage early detection and prompt treatment of illness have demonstrated that mass media and other channels of communication can be effective in reducing the risk of serious illness (15).

In order to be effective, an educational program must be tailored to the targeted audience's needs. Health education activities must take into consideration the physical, behavioral, demographic, psychosocial, and

cultural characteristics of the target audience. In order to ensure that materials are relevant to community needs and interests, educational programs must be developed from the community perspective, and members of the target audience should be included in all phases of the program planning process. Providers are often ill-prepared to communicate the complexities of cancer care to their diverse patient populations; constraints of the medical care system can also impede delivery of care (17).

Oncology-certified nurses specializing in the care of cancer patients play pivotal roles in the delivery of cancer education and treatment. Partnering with Registered Professional Nurses and Advanced Practice Nurses, whose practice arenas involve primary care, these nursing professionals share the burden of integrating ethnic and cultural considerations into best practice models. Nursing shortage issues compound barriers to successful implementation of programs and will require ongoing evaluation and support. Currently, several pending New Jersey Senate and Assembly bills speak to increasing appropriations for nursing programs and nurse-retention programs. (A3345, S2204, A3346, S2205, A3691, S2412, A3193, S2300, A3887, S2443)

To improve these aspects of access to cancer care, the Access and Resources Subcommittee proposes the goal, objectives, and strategies outlined below.

GOAL AC-4:

Enhance current public and professional education efforts to increase access and reduce barriers to cancer prevention, detection, and treatment.

Objective AC-4.1:

To identify strategies to increase cancer service access and resources for all populations through public education.

Strategies:

- (AC-4.1.1) Investigate the efficacy of educational and promotional materials designed to improve access to cancer services with regard to literacy level, language, and culture-specific communication media.
- (AC-4.1.2) Conduct a survey of cancer patients to ascertain awareness of appropriate providers, telephone and/or internet information lines, clinical trials, and transportation services.
- (AC-4.1.3) Work with the Department of Education to develop curricula for Cancer Awareness Week.
- (AC-4.1.4) Collaborate with the New Jersey Commission on Cancer Research on a review of the New Jersey Cancer Resource Book and assist with updates.
- (AC-4.1.5) Disseminate the New Jersey Cancer Resource Book to community organizations, including assisted-living facilities.
- (AC-4.1.6) Promote awareness of health insurance benefits for cancer prevention, detection, and treatment.
- (AC-4.1.7) Educate the public regarding the purpose and importance of participating in clinical trials for cancer, with special emphasis on addressing the concerns of minority populations.

Objective AC-4.2:

To identify strategies to increase cancer service access and resources for all populations through professional education, including health systems, e.g., hospitals, health plans, clinicians.

Strategies:

- (AC-4.2.1) Increase the number of oncology-certified nurses and the number of nurses in the state who hold membership in the Oncology Nursing Society.
- (AC-4.2.2) Launch a statewide educational campaign focusing on cancer prevention, early detection, treatment, and clinical trials.
- (AC-4.2.3) Educate all healthcare professionals on cancer screening guidelines.
- (AC-4.2.4) Address special cancer-related issues of minority and underserved populations at continuing professional education programs.
- (AC-4.2.5) Encourage health plans to promote awareness of appropriate cancer prevention screening intervals and health benefits.
- (AC-4.2.6) Develop and disseminate information to employers/employees regarding the availability of health benefits for cancer services.

Objective AC-4.3:

To identify cancer-related deficiencies in the healthcare system and propose solutions for recruiting more healthcare professionals in New Jersey, particularly Registered Professional Nurses.

Strategies:

- (AC-4.3.1) Develop a plan for recruiting more healthcare professionals in New Jersey.
- (AC-4.3.2) Develop a plan for educating students, Grades K–12, about healthcare careers.
- (AC-4.3.3) Advocate for state funding for professional healthcare training.
- (AC-4.3.4) Promote incentive programs for advanced-level training of healthcare professionals.

Principal Change Agents: The following organizations will contribute to the implementation of the access and resources strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: AC-1.1.1; AC-1.2.1; AC-1.2.2; AC-2.1.1; AC-2.1.2; AC-2.1.3; AC-2.1.4; AC-2.1.5; AC-2.1.6; AC-2.1.7; AC-3.1.1; AC-3.1.2; AC-3.1.3; AC-3.1.4; AC-3.1.5; AC-3.1.6; AC-3.1.7; AC-4.1.1

New Jersey Society for Public Health Education: AC-1.3.1

University of Medicine and Dentistry of New Jersey – New Jersey Medical School: AC-1.1.1; AC-1.2.1; AC-1.2.2; AC-1.3.1

University of Medicine and Dentistry of New Jersey – School of Public Health: AC-1.1.1; AC-1.2.1; AC-1.2.2; AC-1.3.1; AC-2.1.1; AC-2.1.2; AC-2.1.3; AC-2.1.4; AC-2.1.5; AC-2.1.6; AC-2.1.7

ACCESS/RESOURCES

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1. Improve access to cancer-related care and resources	1.1: Identify ethnic and geographic disparities	AC-1.1.1						
		AC-1.1.2						
		AC-1.1.3						
	1.2: Develop solutions	AC-1.2.1						
		AC-1.2.2						
		AC-1.2.3						
	AC-1.2.4							
2. Promote public awareness	2.1: Identify and enhance communication	AC-2.1.1						
		AC-2.1.2						
		AC-2.1.3						
		AC-2.1.4						
		AC-2.1.5						
		AC-2.1.6						
		AC-2.1.7						
3. Improve transportation	3.1: Identify obstacles	AC-3.1.1						
		AC-3.1.2						
		AC-3.1.3						
		AC-3.1.4						
		AC-3.1.5						
		AC-3.1.6						
	AC-3.1.7							
4. Enhance current education efforts	4.1: Strategies to increase access and resources through public education	AC-4.1.1						
		AC-4.1.2						
		AC-4.1.3						
		AC-4.1.4						
		AC-4.1.5						
		AC-4.1.6						
		AC-4.1.7						
	4.2: Strategies to increase access and resources through professional education	AC-4.2.1						
		AC-4.2.2						
		AC-4.2.3						
		AC-4.2.4						
		AC-4.2.5						
		AC-4.2.6						
	4.3: Identify deficiencies	AC-4.3.1						
		AC-4.3.2						
		AC-4.3.3						
		AC-4.3.4						
			Target Completion Date					

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CHAPTER 2. Advocacy

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ADVOCACY

IMPORTANCE OF ADVOCACY FOR CANCER PREVENTION AND CONTROL

Cancer is a political, as well as a medical, social, psychological, and economic issue. Cancer is a personal, tangible, and powerful issue for millions of Americans and thousands of New Jerseyans. Every day legislators make decisions that impact the lives of cancer patients, survivors, their families, and future cancer patients (1). To influence those decisions positively, the *Comprehensive Cancer Control Plan for New Jersey* incorporates advocacy as a major strategy to promote beneficial policies, laws, and regulations for those affected by cancer.

Advocacy is the pursuit of influencing outcomes – including public policy and resource allocation decisions within political, economic, and social systems and institutions that directly affect people’s lives (2). The goal of advocacy for this *Plan* is to promote

public policies at all levels of government that support cancer prevention and detection programs, provide access to care, and enhance quality of life for those affected by cancer.

While cancer issues are increasingly attracting attention on the legislative front, additional advocacy work remains to be done by the Task Force and its workgroups and subcommittees (3). Present legislative priorities in the cancer arena will focus on advancing the *Plan* and ensuring that all residents have access to education, screening, and quality cancer care. Specific advocacy goals, objectives, and strategies are also cited within each site-specific chapter of the *Plan*. However, the following overarching advocacy goals, objectives, and strategies reflect the most urgent and comprehensive actions needed to implement and sustain this ambitious state plan.

The recommendations of the Advocacy Subcommittee are summarized below for the following three topics in priority order:

- Development of *internal structure and funding* for cancer awareness, education, and early detection programs and access to care.
- Advocacy for increased *access* to cancer care, prevention, early detection, and awareness programs.
- Advocacy for reduced cancer-related *health disparities* among minorities and the medically underserved.

GOALS, OBJECTIVES AND STRATEGIES

Overall Goal: Promote public awareness of cancer prevention, early detection and treatment in New Jersey.

INTERNAL STRUCTURE AND FUNDING FOR CANCER ADVOCACY

Our nation has made remarkable progress since the war against cancer began three decades ago. Some cancers have been cured, while others are being detected earlier and treated more effectively. The National Cancer Institute estimates that approximately 8.9 million Americans with a history of cancer were alive in 1997 (4). In fact, for the first time since 1990, cancer death rates are declining. Yet, there is a crisis of confidence in the capacity of our medical system to treat those with chronic and life-threatening illnesses such as cancer. Efforts to define quality care must underscore the fact that

41 million Americans are uninsured and many millions more are underinsured (5).

A highlight of the February stakeholders conference on the Canadian Strategy for Cancer Control was an impassioned presentation by Bob Rae, former Prime Minister of Ontario. Rae first noted the need for a sense of focus and priority. He then observed that the most immediate problem was one of human resources and the setting of national objectives (6). To build and support the advocacy component of the *Plan* as outlined, the Advocacy Subcommittee recommends building an infrastructure to foster its successful implementation.

GOAL AD-1:

To advocate for funding of and support for the *Comprehensive Cancer Control Plan*, including cancer awareness, education, and early detection programs, as well as access to care.

Objective AD-1.1:

To identify, engage, and involve interested public and private parties, institutions, and agencies to garner ongoing support of the *Comprehensive Cancer Control Plan*.

Strategies:

- (AD-1.1.1) Build cancer advocacy capacity through recruitment of identified interested parties. Parties initially identified include, but are not limited to, media, legislators, insurers, pharmaceutical companies, healthcare professionals, corporations, state agencies, and other key decision-makers.

- (AD-1.1.2) Identify champion(s), e.g., patients and patients' families, to advocate on behalf of the *Comprehensive Cancer Control Plan*.

Objective AD-1.2:

To educate legislative members and staff about the importance of funding cancer prevention and control programs.

Strategies:

- (AD-1.2.1) Charge the Task Force on Cancer Prevention, Early Detection and Treatment to create an Advocacy Ad Hoc Committee, comprised of a representative from each of the Task Force workgroups, to address the legislative initiatives cited within each respective chapter of the *Comprehensive Cancer Control Plan*.
- (AD-1.2.2) Work with partner organizations and coalitions to build and continue support for cancer education, early detection, and access to care.

ADVOCACY FOR ACCESS TO CANCER CARE

In 1999, in accordance with its charge, the President's Cancer Panel reviewed the evolution of the National Cancer Program and considered how the nation should move forward to more rapidly reduce the burden of the disease. It was decided that the equal importance of the research and delivery components of the National Plan on Cancer be recognized; that the current barriers preventing quality cancer care from reaching people in all neighborhoods of the nation must be removed; and that the unequal burden of cancer carried by the poor, ethnic minorities, and the underserved be relieved (7).

variety of roadblocks to accessing prevention, early detection, and treatment services. For example, lack of adequate insurance may impede access to cutting-edge treatments provided in a clinical trial or to prevention or early detection tools that have long been accepted by the medical community. Access to needed services can also be adversely affected by reimbursement practices (8). At present, New Jersey has an agreement with the ten largest insurers doing business in the state. This agreement stipulates that residents of New Jersey will have insurance coverage for routine patient costs associated with all phases of cancer clinical trials. This novel agreement, the first of its kind in the nation, has been successful in accessing more patients to clinical trials in New Jersey.

Residents of New Jersey, especially cancer patients and their families, experience a

GOAL AD-2:

To advocate for increased access to quality cancer care, prevention, early detection, and awareness programs.

Objective AD-2.1:

To advocate for providing to all New Jerseyans adequate health insurance coverage relating to cancer prevention and control.

Strategies:

- (AD-2.1.1) Assess current New Jersey insurance coverage for cancer prevention, detection, and treatment to identify gaps.
- (AD-2.1.2) Educate legislators and insurance companies on identified gaps in cancer coverage.
- (AD-2.1.3) Monitor emerging issues related to adequate health insurance for cancer care and identify those issues for possible position development, e.g., undocumented citizen healthcare.

Objective AD-2.2:

To assure that cancer patients have access to quality prevention and cancer care, including both current therapies and treatments provided through high-quality, peer-review clinical trials.

Strategies:

- (AD-2.2.1) Assess and/or review current and pending cancer-related legislation.
- (AD-2.2.2) Advise legislative members and staff of identified cancer-related needs.
- (AD-2.2.3) Continue to make policy-makers aware of data on cancer-related issues such as reimbursement.

Objective AD-2.3:

To create a state-level service that would provide a centralized resource for cancer information

Strategies:

- (AD-2.3.1) Evaluate current cancer resource information systems.
- (AD-2.3.2) Support and cooperate with the appropriate governmental body to develop a state-level cancer resource information system service.
- (AD-2.3.3) Advocate for funding of a centralized cancer resource information system in New Jersey.

**ADVOCACY TO REDUCE DISPARITIES -
THE UNEQUAL BURDEN OF CANCER**

In order for a comprehensive health agenda to be truly effective in reducing cancer incidence and mortality, it must address all populations. We cannot address the differences in the burden of cancer for minority, poor, and medically underserved populations without creative interventions to overcome the barriers to care that threaten our ability to effectively reach and serve these populations.

Cancer in Minorities

Overall, black men in New Jersey and the U.S. are more likely to develop and die from cancer than persons of any other racial and ethnic group. (See The Burden of Cancer in New Jersey for more information.) During 1992-1998, the U.S. incidence rates for all cancer sites was highest among blacks, followed by whites, Asian/Pacific Islanders, Hispanics, and American Indians/Native Alaskans. U.S. mortality rates during the same time period were also highest among blacks, followed by whites, American

Indians/Native Alaskans, Hispanics and then Asian/Pacific Islanders. Despite the high rates of incidence from all cancers combined from 1992-1998, rates among blacks, Hispanics and whites decreased while it remained relatively stable among American Indians/Native Alaskans and Asian/Pacific Islanders. Similarly, mortality rate for all cancer sites decreased annually among blacks, Asian/Pacific Islanders, whites and Hispanics while leveling off among American Indian/Native Alaskans (4). Many disparities among cancer sites also exist and are detailed in the site-specific chapters.

These disparities must be addressed as part of any comprehensive cancer control plan.

Population Demographics Adding to the Cancer Burden

Cancer can strike at any age, but approximately 77% of all cancers are diagnosed at ages 55 and older (4). The American population is graying, with a growing percentage of people now in their 60s and older. With the oncoming retirement of the Baby Boomers, the number of

Americans over age 65 will double in the next 30 years. At current rates, new cancer cases will rise dramatically, causing cancer to surpass heart disease as the nation's leading killer (8). A higher percentage of retirement-

age New Jerseyans have cancer and die of it than in the nation as a whole. Among those 65 and older, the cancer rate is 13% higher among men, 12% higher among women, as compared to the national average (9).

GOAL AD-3:

To reduce cancer-related health disparities among minorities, seniors, and the medically underserved.

Objective AD-3.1:

To advocate for a healthcare system that provides cancer services in a humane, patient friendly, and culturally appropriate manner.

Strategies:

- (AD-3.1.1) Advocate for funding toward increased numbers of knowledgeable and competent navigators for cancer patients and families to help access and navigate the healthcare system.
- (AD-3.1.2) Advocate for organized healthcare systems that reduce fragmentation of available cancer services.
- (AD-3.1.3) Advocate for required quality assurance standards for cancer screening, diagnostic tests, treatment, rehabilitation, and palliation services and therapies that would be available and cost effective for all underserved and seniors.

Principal Change Agents: The following organization will contribute to the implementation of strategies outlined above. This list is not mutually exclusive.

American Cancer Society

ADVOCACY

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Funding of and support for the Comprehensive Cancer Control Plan	1.1: Involve key stakeholders to garner ongoing support	AD-1.1.1						
		AD-1.1.2						
	1.2: Educate legislative members and staff about importance of funding	AD-1.2.1						
		AD-1.2.2						
2: Advocate for increased access to quality cancer care	2.1: Advocate for adequate health insurance coverage	AD-2.1.1						
		AD-2.1.2						
		AD-2.1.3						
	2.2: Provide access to current therapies and treatments	AD-2.2.1						
		AD-2.2.2						
		AD-2.2.3						
	2.3: Create a centralized resource for cancer information	AD-2.3.1						
		AD-2.3.2						
		AD-2.3.3						
3: Reduce cancer-related health disparities	3.1: Advocate for humane, patient friendly and culturally appropriate health care services	AD-3.1.1						
		AD-3.1.2						
		AD-3.1.3						

Target Completion Date

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CHAPTER 3. Palliation

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PALLIATION

DEFINING PALLIATION IN NEW JERSEY

The first challenge facing the Palliation Subcommittee of the Overarching Issues Workgroup was developing a definition of palliative care that was operational, yet inclusive of a variety of perspectives. Subcommittee members noted a lack of consensus in the healthcare world on the meaning of the term *palliative* care. One widely accepted definition – an early definition developed by the World Health Organization (WHO) – begins, “Palliative care is the active total care of patients whose disease is not responsive to curative treatment...” A major drawback with this definition, in the subcommittee’s view, was the limitation of access to palliative care to those at the end of life, when others with chronic rather than terminal illness may also benefit. Subsequently, in 1990, WHO suggested a more global approach stating, “...control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment.” It is this latter, broader definition that the Palliation Subcommittee has chosen as a model for its own definition.

Another issue considered by the subcommittee was the relationship of palliative care to hospice care and a tendency among professionals in the two fields to view their efforts as mutually exclusive. The impact of reimbursement issues on palliative care was a third issue considered. Other challenges in palliative care arise from cultural, ethnic, racial, and religious differences. In developing a definition that was professionally inclusive enough that the

interdisciplinary approach would not become lost in the more familiar medical model hierarchy, subcommittee members strove to be sensitive to these issues and to the resultant political implications.

Acknowledging that those with cancer are increasingly *living with it* rather than (quickly) *dying from it*, the subcommittee concurred that palliative care was certainly indicated for patients whose cancers were responsive to curative treatment, as well as for those in need of end-of-life care. For patients with cancer at any stage, the benefits of care that recognizes psychological distress and spiritual needs as well as physical symptoms are readily apparent. In recognition of these deliberations, the subcommittee proposes the following definition of palliative care:

“Palliative care is a coordinated, interdisciplinary approach to healthcare that enhances the quality of life of patients with cancer and other illnesses. It targets the physical and psychological symptoms and spiritual needs of patients from the time of diagnosis to end-of-life care in all settings.”

(Palliation Subcommittee, 2001)

Note that through the phrase, “from time of diagnosis to end-of-life care in all settings” subcommittee members intend to include both those with both chronic and terminal illness as appropriate recipients of palliative care.

IMPORTANCE OF PALLIATION IN CANCER CARE

The first hospice opened in New Haven, Connecticut, in 1974, inaugurating the hospice movement in the United States. The mission of a hospice was to allow patients to live as long as possible and then to die with

the basic elements of a good death: care, communication, continuity, control, calmness, and closure (1). Today, the premise of hospice has evolved to *palliation*, a term that encompasses all stages along the continuum of care, including improving and maintaining a patient's comfort, dignity, and quality of life, whether in an inpatient or outpatient setting. (See Childhood Cancer Chapter 5 for additional information about Palliation.)

Palliation is frequently described as managing the physical, emotional, and spiritual needs of both patient and family. This comprehensive approach requires a multidisciplinary team for care, including nursing, pharmacy, social work, volunteer services, pastoral care, nutrition, arts, physical therapy, and medicine (1;2).

Palliative care is likely to become the norm of practice in mainstream U.S. healthcare in the coming decade (3) and is a key issue in cancer control. As noted earlier in this plan, the American Cancer Society estimates that 41,100 new cancer cases will be identified and 17,800 cancer deaths will occur in New Jerseyans in 2002 (4). In a recent study of veterans with cancer, it was found that at any time 10% to 20% of the study population urgently needed intensive palliative care (5). The potential for cancer patients needing palliative care services in New Jersey is very high.

Despite advances in palliative care in the past two decades, many cancer patients continue to suffer from unmanageable symptoms, including an unacceptable 70% to 90% experiencing acute pain (6). Cancer patients receiving palliative care reported prevalence of lack of energy, pain, dry mouth, shortness of breath, and difficulty sleeping (5). Pain includes physical and spiritual manifestations (feelings of abandonment, anger, betrayal, despair, fear,

guilt, meaninglessness, regret, self-pity, and sorrow/remorse) (1). Patient barriers to effective pain management include a reluctance to report pain, fear that pain signifies advancing disease, and the desire to be a "good" patient and not bother the physician with complaints of pain (1).

Every year the number of New Jerseyans who die with cancer in an inpatient setting is decreasing. In 1989, approximately 63% of New Jerseyans who died from cancer were inpatients, compared to 42% in 1998 (7). The percentage of Medicare cancer patients enrolled in hospice declined from 75.6% in 1992 to 57.4% in 1998. It is apparent that patients with cancer are increasingly substituting their residence for the hospital as a place of death.

Additionally, the cost of palliative care is increasing. Medicare hospice expenditures climbed from \$205 million in FY1989 to \$2.1 billion in FY1998 (8). Medicaid hospice expenditures rose from \$1.5 million in FY1987 to \$197.2 million in FY1999. New Jersey was the 35th state to offer hospice under Medicaid in 1992 (8). Expenditures for palliative care will continue to rise due to an aging population, increasing interest and concern about palliative care and end-of-life issues, and rising healthcare costs.

In the next decade, barriers to effective palliative care must be alleviated. The Palliation Subcommittee determined that addressing lack of awareness among healthcare professionals and the public about palliative care is a priority in New Jersey. Secondly, access to palliative care must be increased. Both these issues are described in further detail in the remainder of this chapter, and recommendations for improvement are outlined.

The recommendations of the Palliation Subcommittee are summarized below for the following topics in palliative care presented in priority order:

- Education
- Access

GOALS, OBJECTIVES AND STRATEGIES

Overall Goal: Increasing awareness of and access to palliative care.

EDUCATION ON PALLIATIVE CARE

In order to influence quality of life in a positive manner, there must be clarity regarding the goals of care. To achieve clarity, the clinician must be knowledgeable about options that exist in the domain of palliative care along with the primary therapies. Just as important, the patient must also be aware of available options.

In the palliative care arena, diverse treatment options are available for the seriously or terminally ill. Yet choices for patients and surrogates will always be limited to those offered by the physician or requested by the patient or a surrogate (9). Failure to provide survival estimates may also limit patient choice about palliative care. According to a recent study, physicians reported that even if patients with cancer requested survival estimates, clinicians provided a frank estimate only 37% of the time, rather providing no estimate, a conscious overestimate, or a conscious underestimate most of the time (63%) (10).

The challenges presented to patients and their families at time of diagnosis, during treatment stages, and continuing into survivorship years, are significant not only physically, but also psychosocially and spiritually. Therefore, effective, responsible care requires the integration of counseling into the treatment plan whereas medical professionals may regard this aspect of care as either unimportant or secondary, rather than as a core component. Another problem impeding broader access to palliative care is the fact that patients and their surrogates may not be aware of the care options that exist (11).

Despite the many societal and professional barriers to effective pain management, the Palliation Subcommittee has identified physician knowledge gaps in pain management and symptom control and misconceptions regarding pain management as the top priority to improve palliative care in New Jersey. In recent years, several medical and nursing schools have added education regarding palliative care concepts to their curricula. Many require that a hospice rotation be included in the clinical experience, since hospice is pure palliative care. The number of professionals certified in palliative care may be expected to increase, as additional educational opportunities in the field become more numerous.

Initiatives have also been undertaken to build public awareness. In 2000, Bill Moyers' four-part series entitled "On Our Own Terms" reported on the growing movement in America to improve care for people who are dying (Films for Humanity and Sciences). Both the newspaper and movie industries have explored quality-of-life issues related to aggressive, curative treatments as well as supportive care for the terminally ill (www.lastacts.org).

Many state policy-makers are working to improve care at the end of life, hoping to insulate their states against efforts to secure the right to assisted suicide. "People have to feel confident that the health care system will take good care of them when they are dying," says Assemblywoman Helen Thomson (D-California). "Lack of faith in that system is what moves people to desperate measures" (12). There are legal barriers to quality end-of-life care - one example among several relates to adequate pain management.

Marilyn Webb writes, “Adding to American physician’s apprehension about using narcotics is stringent and increasing pressure from law-enforcement agencies. Indeed, by now the legal scrutiny provoked by narcotics use makes even suffering patients and their families fearful of using opioid drugs and it has left doctors terrified” (13). Legislators can help remove barriers, which would benefit every constituent in their districts. Knowledge of the issues is imperative to understanding the changing needs.

Although small steps have been made toward improving understanding of and access to palliative care, the need for better care that promotes quality of life continues to grow. The transition, however, from a medical model of care to a holistic one requires a

paradigm shift in healthcare philosophy. Healthcare professionals and the public need support in understanding dying not as a failure of medicine, but as a natural part of life. People are living longer with chronic illnesses and are dying more slowly. Healthcare professionals need to respond to the challenge of supporting quality of life in addition to length of life. Education is the first step in understanding suffering. With knowledge comes the power to truly affect quality of life along the entire continuum of care and most intensively and poignantly at the end of life. Therefore, the Palliation Subcommittee proposes the following educational goal, objective, and strategies as next steps in improving palliative care in New Jersey through provider education.

GOAL PA-1:

To integrate knowledge of palliative care into professional, public health, and legislative systems.

Objective PA-1.1:

To educate and identify incentives for legislators, healthcare professionals, and the general public regarding the right to access palliative care and the benefits of comprehensive palliative care in all settings.

Strategies:

- (PA-1.1.1) Integrate training on palliative care into primary and continuing education for practicing professionals.
- (PA-1.1.2) Develop a public education plan on palliative care for targeted populations based on capacity and needs assessments.
- (PA-1.1.3) Educate state legislators who can serve as advocates in supporting palliative care policies.

ACCESS TO PALLIATIVE CARE

Members of the Palliation Subcommittee hold that all patients in New Jersey are entitled to access palliative care services, regardless of the chronic illness from which they are suffering and regardless of the setting in which they may be found – whether in their own homes; long-term care facilities, such as nursing homes, mental institutions, centers for the mentally and physically challenged; hospitals; assisted-living facilities; boarding homes; state veterans’ hospitals; or prisons. Many of these patients will have family members and/or significant others (hereafter referred to as the family). Family members, as well, are entitled to the supportive care services offered by palliative care.

Due to conflicting regulations, especially within institutional settings, patients may have difficulty receiving appropriate palliative care services, even when the patient and family desire such services. Healthcare providers, as well, often become frustrated with the system, as they cannot provide the care the patient and family desire and deserve. On the other hand, even when the focus on curative care is no longer the avenue of choice, some healthcare providers may still find it difficult to offer palliative care. Other times, the distinction between curative and palliative care may not be clear-cut, and care approaches may fluctuate between the two.

While Medicare and a number of insurance and managed care plans cover hospice, palliative care services are often covered only indirectly under another aspect of care, if at all. At other times, palliative care may be offered as an option, but another option actually becomes the payer. In the latter case, care needs to be taken that the palliation aspect is not compromised or lost entirely. Another concern is that a patient may be on hospice too long or not long enough. In

reality, palliative care services and hospice should be part of a continuum of care, in which patients and families can make choices they are comfortable making and ready to make, with support and guidance from healthcare professionals. Patients and families need to be empowered to participate in healthcare decisions.

Further dialogue needs to take place with insurance companies and managed care plans as to the benefits of palliative care services for those in need and the long-term savings to payment sources. Government agencies and institutions also need to be educated as to the importance of palliative care, the long-term savings, and their obligations for reasonable reimbursement and/or provision of these services in government institutional settings.

In addition to institutional and financial barriers to access, numerous patient and family barriers have been identified (14). Socioeconomic backgrounds, cultural backgrounds and practices, personal values and beliefs, and religious or spiritual belief systems can influence perception of palliative care services (15). For widespread acceptance of palliative care to occur, a multi-pronged effort is needed to engage healthcare providers, voluntary community-based organizations, faith-based groups, and other identified entities that are in a position not only to stimulate establishment of palliative care in healthcare settings in their communities (3), but also to provide information to and support for patients and their families.

Research has been done on cost savings and quality-of-life outcomes for patients and families that need and receive palliative care services. Comfort from pain, relief of symptoms, emotional and spiritual supports are only a few of the benefits for patients. For example, it is important to recognize pain management as the fifth vital sign, along with

blood pressure, temperature, pulse, and respiration. Prevention and/or reduction of physical, emotional, and financial problems, as well as prevention of long-term psychosocial problems, are but a few of the benefits for families. Social workers and pastoral counselors within healthcare settings can be helpful in obtaining resources to assist patients and families in obtaining needed palliative care services.

Existing data have been compiled for this *Plan*. Future surveys or research projects can focus on gaps in the existing data. Foundations, grants, insurance companies, government agencies, universities, and healthcare centers may be avenues for future funding. Commissions or task forces, such as that charged with producing this *Plan*, may be another avenue of study and recommendations for appropriate funding.

GOAL PA-2:

To ensure that palliative care services are accessible to cancer patients and others with chronic illnesses.

Objective PA-2.1:

To ensure reimbursement for palliative care services.

Strategy:

- (PA-2.1.1) Investigate palliative care reimbursement initiatives and engage insurance companies in further discussion of reimbursement for palliative care services including psychosocial counseling for the patient and the patient's family.

Objective PA-2.2:

To develop standards for palliative care.

Strategy:

- (PA-2.2.1) Link with national organizations that can help frame the palliative care issue on a national scale.

Objective PA-2.3:

To identify, prioritize, and reduce the system barriers to palliative care services.

Strategies:

- (PA-2.3.1) Collect existing data and identify gaps in available palliative care services.
- (PA-2.3.2) Develop strategies to address the gaps in palliative care services.

Objective PA-2.4:

To identify, prioritize, and reduce personal barriers to palliative care services.

Strategy:

- (PA-2.4.1) Partner with interdisciplinary and grassroots organizations to alleviate personal barriers to palliative care.

Principal Change Agents: The following organizations will contribute to the implementation of palliative care strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: PA-2.3.2

New Jersey Hospice and Palliative Care Organization: PA-1.1.1; PA-1.1.2; PA-1.1.3; PA-2.1.1; PA-2.2.1; PA-2.3.1; PA-2.3.2

PALLIATION

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Integrate palliative care	1: Educate all constituencies regarding rights and benefits of palliative care	PA-1.1.1						
		PA-1.1.2						
		PA-1.1.3						
2: Ensure accessibility to palliative care	2.1: Reimbursement	PA-2.1.1						
	2.2: Palliative care standard development	PA-2.2.1						
	2.3: Reduce system barriers	PA-2.3.1						
		PA-2.3.2						
	2.4: Reduce personal barriers	PA-2.4.1						

Target Completion Date

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CHAPTER 4. Nutrition and Physical Activity

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NUTRITION AND PHYSICAL ACTIVITY

IMPORTANCE OF NUTRITION AND PHYSICAL ACTIVITY FOR CANCER PREVENTION AND CONTROL

The role of diet in cancer etiology and prevention is well established. A panel of experts commissioned by the World Cancer Research Fund and the American Institute for Cancer Research concluded that between 30% and 40% of all cancers are preventable by dietary means, physical activity, and maintenance of appropriate body weight (1). Establishing healthy eating patterns can play a major role in cancer prevention, mainly because this is a potentially modifiable behavior. There is also increasing evidence that physical activity may be inversely related to some cancers (2). Therefore, the introduction of healthy eating patterns and physical activity at any time will promote overall health and greatly reduce the risk of cancer.

Evidence-based National Dietary Guidelines for cancer prevention have been issued by various organizations. Overall, they all recommend a reduction in fat intake, particularly from animal sources, an increase in fiber intake, the inclusion of a variety of fruits and vegetables in the daily diet, to be physically active and maintain a healthy weight, to consume alcoholic beverages in moderation, if at all, and to minimize the consumption of salt-cured, salt-pickled, or smoked foods.

Less well known is the role played by diet and physical activity during the various phases of cancer survivorship – active treatment phase, recovery phase, health maintenance phase, and for some, a phase of living with advanced cancer. After a cancer diagnosis, many survivors look actively for information on dietary choices, alternative therapies,

including supplements, and physical activity to help them gain some measure of control over their condition and improve their symptoms. Survivors have evolving needs and challenges regarding nutrition and physical activity throughout the phases of survivorship. The current scientific evidence on nutrition and physical activity was recently reviewed by a panel of experts organized by the American Cancer Society (3). In general, the panel concluded that adequate dietary intake can improve nutritional status in virtually all cancer survivors and recommended that survivors follow the basic National Dietary Guidelines described above for a healthy diet. Yet clearly, further research in this area is imperative. While the important role of cigarette smoking in cancer etiology and prevention cannot be underestimated, for the great majority of Americans who do not smoke cigarettes, dietary and physical activity behaviors are the most important modifiable determinants of cancer risk (4).

Nutrition and Physical Activity in New Jersey

As noted in the introductory section to this *Plan* on “Cancer Burden in New Jersey,” the incidence and mortality for certain cancer types is higher in New Jersey than the national average. The Healthy New Jersey 2010 Report (5) focuses on the following goals for nutrition and health:

1. **Objective:** To increase the percentage of persons aged 18 and over eating at least five daily servings of fruits and vegetables (including legumes) to 35.0%.
2. **Objective:** To reduce the percentage of persons aged 18 and over who are overweight but not obese to 27.6% for all adults.

3. **Objective:** To reduce the percentage of persons aged 18 and over who are *obese* to 12.0% of all adults.
4. **Objective:** Increase the percentage of persons aged 18 and over who participate in frequent, leisure-time *physical activity* during the past month to 42.5%.

Consumption of Fruits and Vegetables. As shown in Table 1, according to Behavioral Risk Factor Surveillance System (BRFSS) data, only 27.4% of New Jersey adults reported consuming fruits and vegetables at least five times a day in the year 2000. Although, the proportion of

New Jersey residents eating 5-a-day is higher than the national average for the total population and for each race, gender, and age subgroups (Table 1), we are still far from the Healthy New Jersey 2010 target of 35%. BRFSS trend data also indicate that the proportion of people eating the recommended five servings of fruits and vegetables has remained essentially stable during the past decade. These data underscore the need for more efficient nutrition interventions to help New Jersey residents achieve this goal. Males, Hispanics, and young New Jersey residents, aged 18 to 24 years, may derive the most benefit from these interventions (Table 1).

Table 1. Proportion of New Jersey residents 18 years and older who reported consuming fruits and vegetables at least five times a day in the year 2000* and specified target % in Healthy New Jersey 2010**

	New Jersey (2000)	Nationwide (2000)	Healthy NJ 2010 Target	Preferred Healthy NJ 2010 Endpoint
Total	27.4	23.1	35	50
By race				
White	27.4	23.4	35	50
Black	27.9	21.3	35	50
Hispanic	24.6	23.2	35	50
Other	35.4	24.9	35	50
By gender				
Male	24.0	18.9		
Female	30.6	26.9		
By age				
18-24	23.3	21.6		
25-34	24.8	19.1		
35-44	24.7	19.8		
45-54	26.6	21.8		
55-64	27.2	26.9		
65+	36.0	31.7		
By education				
< High School	25.5	19.9		
H.S. or GED	25.7	19.6		
Some post-HS	24.7	23.9		
College graduate	31.7	27.8		

*Behavioral Risk Factor Surveillance System data, CDC, 2000

**Healthy New Jersey 2010, New Jersey Department of Health and Senior Services.

Overweight. As Table 2 shows, the proportion of overweight subjects in 2000 was slightly higher in New Jersey than the national average (38.3% and 36.7%, respectively). This is also illustrated in Figure 1, where the prevalence of overweight subjects seems to have been slightly increasing over the last decade. The percentage of overweight males was considerably higher than that of females in the year 2000 (Table 2). The data also reveal differences by race, with blacks reporting the highest prevalence of overweight in the year 2000 (Table 2). Also included in Table 2 are the Healthy New Jersey objectives for reducing the percentage of overweight subjects for the year 2010. The

target percentages shown in Table 2 were based on BRFSS 1996-1999 data and reflect discrepancies by race observed during that period. According to BRFSS data for the years 1996-1999 (data not shown), the percentage of overweight New Jersey residents was highest among Hispanics (41.5%), followed by blacks (38.3%), and whites (36.3%). Although male and black populations appear to have the greatest need for the intervention and research programs, all groups are far from the target 27.6% and could benefit from health promotion activities aiming at achieve long-term healthy body weight.

Table 2. Percentage of New Jersey residents 18 years and older who are overweight (defined as BMI* between 25 and 29.9) in 2000 and specified target % in Healthy New Jersey 2010*****

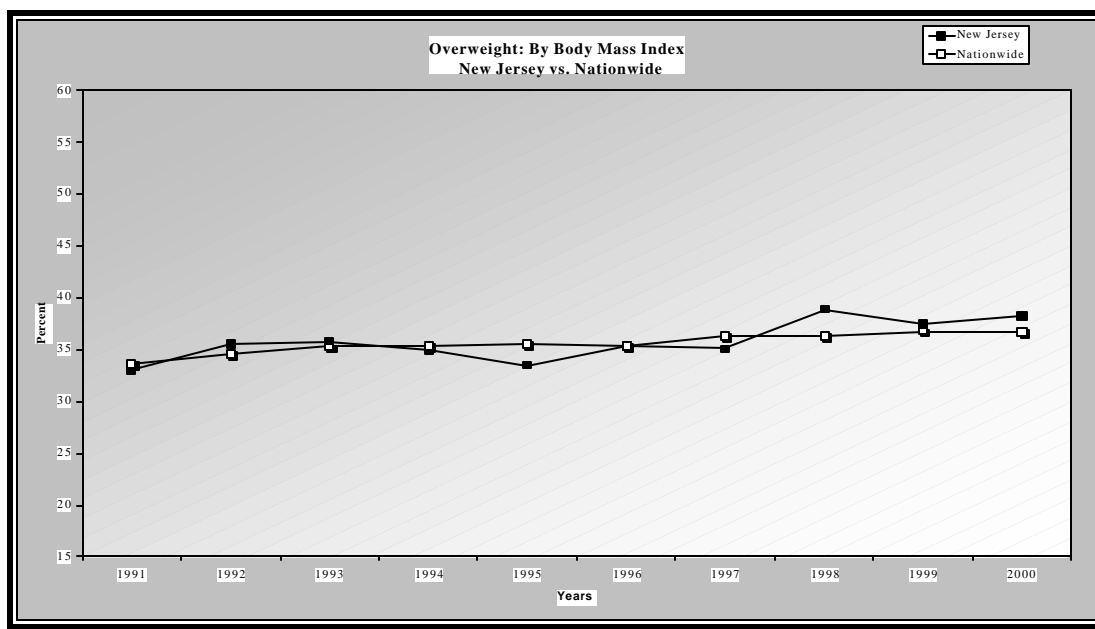
	New Jersey (2000)	Nationwide (2000)	Healthy NJ 2010 Target	Preferred Healthy NJ 2010 Endpoint
Total	38.3	36.7	27.6	25
By race				
White	37.4		28.1	25
Black	44.0		28.4	25
Hispanic	38.9		32.4	25
By gender				
Male	48.4	45.1	36.6	25
Female	28.5	28.5	25.1	25
By age				
18-34	32.7	31.1		
35-49	40.9	38.1		
50-64	40.4	40.7		
65+	40.2	40.0		

* BMI (Body Mass Index) is defined as weight in kilograms divided by height in meters squared (w/h^{**2}).

**Behavioral Risk Factor Surveillance System data, CDC, 2000.

***Healthy New Jersey 2010, New Jersey Department of Health and Senior Services.

Figure 1. Trends in percentages of New Jersey residents who are overweight* versus nationwide, Behavioral Risk Factor Surveillance System, 1991-2000



*All respondents 18 and older who report that their Body Mass Index is between 25.0 and 29.9. BMI is defined as weight in kilograms divided by height in meters squared (w/h^2). Denominator includes all survey respondents except those with missing, don't know, and refused answers.

Obesity. Although New Jersey is closer to the Healthy New Jersey 2010 objective than the national average (Table 3), considerable efforts must still be expended to bring the current obesity prevalence of 18.5% to the Healthy New Jersey 2010 target of 12%. The obesity prevalence is particularly high among blacks (25.8%). Figure 2 illustrates the alarming trend in increasing obesity over the past decade and highlights the need for immediate effective intervention and research to reverse this trend.

Physical activity. The obesity epidemic in the U.S. and in New Jersey is the result of unhealthy diets and lack of exercise. As shown in Table 4, 29% of New Jersey residents reported no leisure-time physical activity, and only 14% engaged in regular and vigorous exercise in the year 2000.

Although the levels of physical activity seem to be similar for males and females, there are striking differences by other demographic characteristics. The level of physical inactivity is particularly high among Hispanics (40%) and is inversely related to education and income. Not surprisingly, stratified analysis by Body Mass Index (BMI) revealed the highest proportion of inactive subjects among those with a BMI of 30+ (obese subjects). Reaching the objective outlined in the Healthy New Jersey 2010 of increasing the percentage of New Jersey adults participating in frequent leisure-time physical activity to 42.5% appears to be a challenge, particularly for certain subgroups, such as the less affluent, less educated, obese, and non-white populations.

Table 3. Percentage of New Jersey residents 18 years and older who are obese (defined as BMI* of 30.0 or greater) in 2000 and specified target % in Healthy New Jersey 2010*****

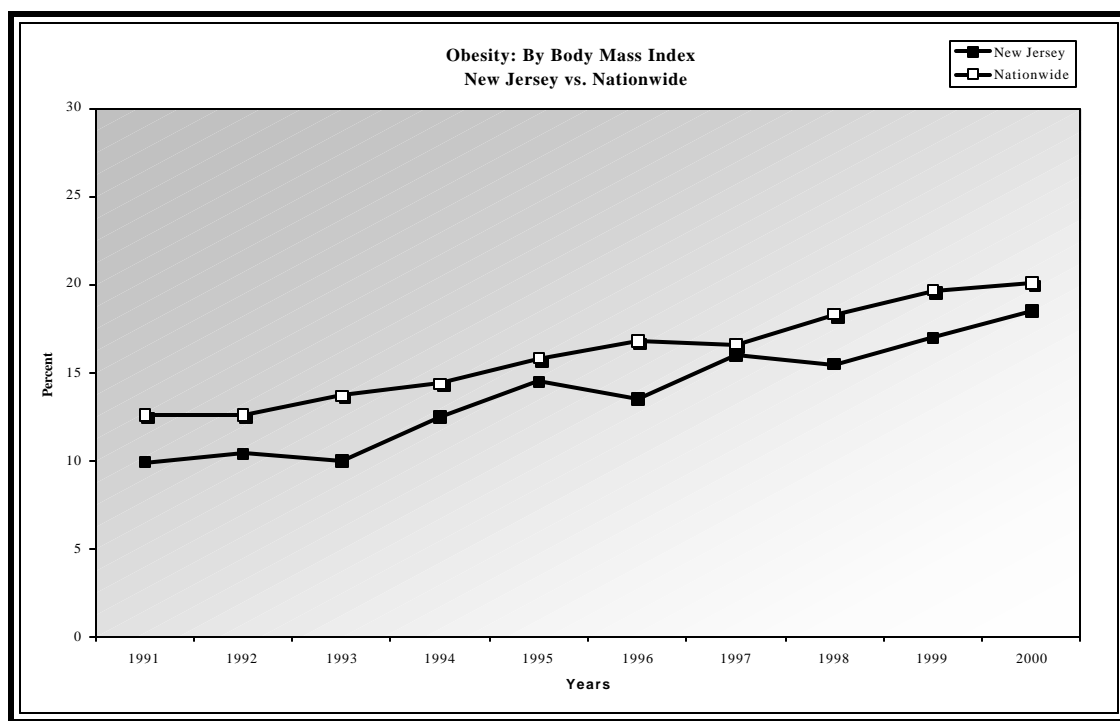
	New Jersey (2000)	Nationwide (2000)	Healthy NJ 2010 Target	Preferred Healthy NJ 2010 Endpoint
Total	18.5	20.1	12	12
By race				
White	17.8		12	12
Black	25.8		15	12
Hispanic	19.8		12	12
By gender				
Male	18.4	20.6	14	12
Female	18.5	19.8	12	12
By age				
18-34	11.9	15.8		
35-49	19.9	22.0		
50-64	24.6	26.7		
65+	20.1	18.2		

* BMI is defined as weight in kilograms divided by height in meters squared (w/h**2).

**Behavioral Risk Factor Surveillance System data, CDC, 2000.

***Healthy New Jersey 2010, New Jersey Department of Health and Senior Services.

Figure 2. Obesity trends in New Jersey versus nationwide, Behavioral Risk Factor Surveillance System, 1991-2000



*All respondents 18 and older who report that their Body Mass Index is 30.0 or more. BMI is defined as weight in kilograms divided by height in meters squared (w/h**2). Denominator includes all survey respondents except those with missing, don't know, and refused answers.

**Table 4. Percentage of subjects participating in four levels of physical activity.
BRFSS 2000, New Jersey adults**

	Inactive*	Irregular**	Regular***	Regular and vigorous****
Total group	29	27	30	14
By gender				
Males	27	27	33	14
Females	31	27	28	15
By race				
White	25	27	31	16
Black	29	32	30	9
Hispanic	40	25	25	10
By age				
18-64	27	27	32	14
65+	35	26	22	18
By education				
< High school	47	26	19	8
High school graduate	35	24	30	11
Some college	24	31	31	14
College graduate	18	34	34	21
By income				
<15,000	46	20	23	11
15,000-24,999	43	23	25	9
25,000-49,999	30	27	30	12
50,000-74,000	23	27	34	16
≥75,000	16	29	34	21
By Body Mass Index				
<25	24	27	32	17
25-29.9	27	28	31	14
≥30	39	24	27	10

*No leisure time physical activity;

**Some activity but <3 times/week or <20 minutes/session;

***3+ times/week, 20+ minutes/session, <50% of capacity;

****3+ times/week, 20+ minutes/session, 50+% of capacity

Source: NJ BRFSS, Center for Health Statistics

The recommendations of the Nutrition and Physical Activity Subcommittee are summarized below for the following three topic areas in priority order:

- Cancer Prevention
- Research
- Cancer Survivorship

GOALS, OBJECTIVES AND STRATEGIES

Overall Goal: To reduce cancer incidence in the State of New Jersey by improving the diet and increasing physical activity among its residents; and to improve survival and quality of life among cancer patients and survivors.

CANCER PREVENTION AND NUTRITION/PHYSICAL ACTIVITY

According to the Centers for Disease Control and Prevention, dietary factors play a major role in the development of many cancers, especially those of the digestive and reproductive organs (5). It has been estimated that approximately one-third of all cancers occurring in the U.S. might be attributed to dietary factors (1). The precise biological impact for any single dietary factor is difficult to determine given the endless number of substances present in diet and the interactions among them. However, we do know that the foods we eat contain substances with carcinogenic and anticarcinogenic potential.

At the present time many aspects of the relationship between diet and cancer are not fully understood. For example, the role of dietary fat as a key factor in cancer development has been recently challenged (6). The type of dietary fat consumed, rather than total fat, seems to be a more important factor in determining cancer risk (2). Nevertheless, the epidemiologic literature provides strong support for a role of fruits and vegetables, whole grains, dietary fiber, and physical activity against some cancers, whereas obesity, alcohol, some fatty acids, and food preparation methods may increase cancer risk (2).

The body of literature showing that diets high in fruits and vegetables are associated with a reduced risk of cancer is large and fairly consistent, particularly for cancer of the gastrointestinal and respiratory tracts (7). A report by a group of experts commissioned by the American Institute for Cancer Research and

the World Cancer Research Fund concluded that increasing consumption of fruits and vegetables from ~250 to 400 g per day may be associated with a 23% decreased risk of cancer worldwide. The numerous constituents in fruits and vegetables, including dietary fiber and phytochemicals (e.g., carotenoids, flavonoids, phytoestrogens, glucosinolates, isothiocyanates, and indoles), or interactions among them, may be responsible for the observed beneficial effect of these foods.

A growing body of evidence suggests that obesity increases the risk of colon and prostate cancer for males and of post-menopausal breast cancer, endometrial, ovarian, gall bladder, and cervical cancer for females. Hormonal mechanisms have been proposed to explain the relationship between body size and cancers of the breast, endometrium, and colon, in particular through increases in estrogens and insulin and insulin-like growth factors (2). These hormonal factors have been implicated in the etiology of breast, endometrial, and colon cancer (2).

Evidence for a role of physical activity in reducing cancer risk is accumulating. A recent systematic review of the epidemiologic literature concluded that the evidence for a protective role of physical activity for colon and breast cancer is convincing, for prostate cancer is probable, for lung and endometrial cancer is possible, whereas for testicular and ovarian cancers evidence is insufficient (8). Several mechanisms have been proposed to explain the beneficial effects of regular physical activity, including modification of endogenous sex and metabolic hormonal levels and growth factors, decreased body fat content, and possibly enhanced immune function (8).

A decrease in physical activity can be linked to the increase of individuals nationwide who are overweight or obese. Labor-saving devices at home and work, fewer safe areas for pedestrians and cyclists, and less emphasis on physical education in schools are just a few examples of factors that have caused a decrease in physical activity. The growing popularity and availability of fast foods and snack foods is increasing caloric intake while physical activity continues to slow.

A recent study found that physically active individuals had lower annual direct medical costs than did inactive people. The cost difference was \$330 per person, based on 1987 dollars. The potential savings if all inactive American adults became physically active could be \$29.2 billion in 1987 dollars, or \$76.6 billion in 2000 dollars (9).

According to the report of the Surgeon General, physical activity also appears to improve health-related quality of life by enhancing psychological well-being and by improving physical functioning in persons compromised by poor health (10).

Several reports have been published that provide suggestions to improve healthy eating habits and increase physical activity to decrease the risks of cancer (10;11). The Surgeon General suggests that consistent influences on physical activity patterns among adults and young people include confidence in one's ability to engage in regular physical activity (e.g., self-efficacy), enjoyment of physical activity, support from others, positive beliefs concerning the benefits of physical activity, and lack of perceived barriers to being physically active. Interventions targeting physical education in elementary school can substantially increase the amount of time pupils spend being physically active in physical education class. For adults, some interventions have been successful in increasing physical activity in communities, worksites, healthcare

settings, and at home (10). The Harvard Report on Cancer Prevention provides steps for prevention of cancer at the individual, community, and government levels. Researchers recommend that individuals foster better dietary habits, exercise moderately, avoid excess alcohol intake, and speak with their doctors about lifestyle decisions that reduce cancer risk. At the community level, nutrition and physical activity in school curricula are recommended as well as mass media campaigns and accessibility for physical activity and nutrition education programs. Governments are advised to support physical and health education for all grades and to monitor food supplement programs for a nutritional balance (11).

Throughout New Jersey, current efforts to address the role of nutrition and cancer are limited, despite attempts to implement suggestions in the cited reports. Programs and services have been instituted to improve the nutrition and physical activity of all New Jersey residents. However, there is no allocation of state funds to any department in state government dedicated to planning comprehensive and statewide programs that coordinate, implement, and evaluate nutrition and physical activity programs.

In New Jersey, the Department of Health and Senior Services and the U.S. Department of Agriculture (USDA) cosponsor the 5 A Day for Better Health Program in partnership with the National Cancer Institute and the Produce Better Health Foundation. Commonly known as "5 A Day," the program is a national effort to achieve the Healthy People 2010 objective to increase the per capita consumption to five or more servings of fruits and vegetables daily. In 1995, representatives from other public sector organizations in the areas of health, nutrition and education, private non-profit organizations, and the food industry were invited to create the New Jersey 5 A Day Coalition. Approximately 30 organizations

participate in the coalition, which in 2001 developed the following mission statement: “The New Jersey 5 A Day Coalition is a diverse group of stakeholders advocating the consumption of 5 or more servings of fruits and vegetables a day, for the purpose of promoting health and improving the quality of life for all New Jerseyans.”

Through the effort and commitment of the 5A Day Coalition, many awareness and educational activities and events take place throughout New Jersey to spread the word about the health benefits of fruits and vegetables. New Jersey residents hear about the importance of 5 A Day at WIC clinics, hospitals, HMO and health clinics, schools, worksites, government offices, churches, produce distributors, farmers markets, supermarkets and health fairs, and other community events.

As mentioned above, all activities and events coordinated by the New Jersey 5 A Day Coalition are directed toward achieving the Healthy New Jersey 2010 Objective to: “Increase the percentage of persons (aged 18 years and over) eating at least 5 daily servings of fruits and vegetables (including legumes) from 27.0% to 35.0%.”

It is widely recognized that nutrition plays a significant role in health promotion and disease prevention. It is also clear that consumers are not only listening, but also attempting to apply the information available to them. The availability of accurate nutrition information and use of well-researched nutrition education tools continues to be important. Age, literacy level, and culturally appropriate tools are needed, as well. While, the plethora of state and national nutrition and physical activity programs provide many opportunities to decrease the cancer risk for New Jersey citizens, a statewide coordinating body does not yet exist. This leads to lack of communication among initiatives and duplicated efforts.

The 5 A Day Program is the only nutrition program that addresses the role of nutrition and cancer prevention at the New Jersey Department of Health and Senior Services. The 5 A Day State Coordinator position is not funded by federal or state funds, specifically for this function. Currently the 5 A Day state coordinator position is supported by the WIC program, which receives funding from the USDA. Therefore, the coordinator cannot devote full-time responsibilities to the 5 A Day program. This lack of funding affects program materials and other resources. At this time, nutrition services in the state of New Jersey are fragmented and gaps in services exist. There is no comprehensive plan for nutrition and the continued need for advocacy for reimbursement of preventive and medical nutrition therapy exists.

The Nutrition and Physical Activity Subcommittee recommends a fully funded comprehensive nutrition unit at the state level to coordinate and improve existing and identified needed programs. The plan also needs to include recognition that many existing health programs include a nutrition component, but lack the resources and direction for successful implementation.

To enhance existing nutrition and physical activity programs/services, the Nutrition and Physical Activity Subcommittee advises that New Jersey residents be educated about healthy eating patterns and exercise. Various nationwide research has shown successful community education (12;13) and worksite education programs (14-16) focusing on the importance of healthy eating patterns and moderate physical activity for cancer prevention. Additionally, school-based curricula (17) have a positive impact on the eating patterns of students. Therefore, the Nutrition and Physical Activity Subcommittee proposes that New Jersey residents be educated about the importance of dietary factors and physical activity to decrease

the risk of cancer through academic, worksite, and community education. Improving access (11) and services provided can enhance existing public health programs. Additionally, high-risk groups, such as certain ethnic groups (15), those with lower incomes, and those at lower educational levels, should be targeted for education about cancer-risk reduction (18). The Nutrition and Physical Activity Subcommittee

also recommends a fully funded comprehensive nutrition program at the state level to coordinate and improve new and existing programs, focusing on high-risk populations. The Nutrition and Physical Activity Subcommittee further proposes the installation of a high-level individual in the state to coordinate and improve existing activities.

GOAL NP-1:

To promote long-term healthy eating patterns, healthy weight, and physical activity for cancer prevention among New Jersey residents.

Objective NP-1.1:

To increase the amount and proportion of healthy foods, especially fruits and vegetables, that New Jersey residents consume each day.

Strategies:

- (NP-1.1.1) Review the New Jersey school curriculum for education about diet and nutrition, including healthy eating patterns, physical activity, and the prevention of cancer. Make recommendations for improvements if and where needed.
- (NP-1.1.2) Conduct an evaluation of food services in educational institutions, day care facilities, and workplaces in order to implement improvements in these services in line with federal guidelines.
- (NP-1.1.3) Increase access to healthy foods, especially for high-risk groups, by supporting state-level nutrition programs, such as WIC, 5 A Day, and Team Nutrition.
- (NP-1.1.4) Assess needs and develop nutrition education programs for cancer prevention among college students.
- (NP-1.1.5) Assess needs and develop nutrition education programs for cancer prevention among Head Start parents and other low-income groups.
- (NP-1.1.6) Create a mass media campaign to promote statewide nutrition programs that encourage consumption of a diet consistent with dietary guidelines.

Objective NP-1.2:

To enhance, or develop where necessary, statewide nutrition programs to help New Jersey residents reduce the risk of developing cancer.

Strategies:

- (NP-1.2.1.) Establish an infrastructure within state government to coordinate and collaborate activities among existing nutrition programs.
- (NP-1.2.2) Incorporate an evaluation component in nutrition education programs to evaluate effectiveness toward modifying behaviors that affect cancer risk.
- (NP-1.2.3) Coordinate and support comprehensive nutritional education programs in allied fields by sponsoring collaboration.

Objective NP-1.3:

To increase frequent, leisure-time physical activity, as consistent with Healthy New Jersey 2010 goals.

Strategy:

- (NP-1.3.1) Educate the public about ways to increase physical activity using existing programs and information sources.

Objective NP-1.4:

To reduce alcohol consumption in the State of New Jersey particularly at high levels.

Strategy:

- (NP-1.4.1) Educate the public about the dangers of heavy alcohol consumption.

RESEARCH ON NUTRITION/PHYSICAL ACTIVITY AND CANCER

Although the importance of diet and nutrition in cancer prevention is well recognized, more scientific information is needed in order to effectively reduce cancer risk through dietary approaches. Three major research areas can be identified. One concerns the effects of different dietary aspects (e.g., individual food items, food groups, food patterns, dietary diversity, nutrients) and physical activity on cancer risk. For example, even the previously accepted concepts that a high-fat diet increases breast cancer risk and a high-fiber diet decreases colon cancer risk have been challenged (7). Although nutritional guidelines for cancer survivors have been issued, there is insufficient information on how certain dietary practices can increase survival. Many dietary constituents and herbs have been developed commercially as diet supplements for the prevention or even cure of cancer based on over- or misinterpretation of data or unscientific extrapolation. The possible efficacy and harmful effects of these products need to be studied.

The second area of research that the Nutrition and Physical Activity Subcommittee recommends concerns the development and evaluation of effective approaches of behavior modification with regard to dietary pattern and physical activity; that is, how to motivate an individual to adopt and maintain healthy eating habits and to exercise regularly and/or what kind of environmental changes are needed to support these changes in the State of New Jersey.

The Nutrition and Physical Activity Subcommittee further recommends research into the etiology of cancer cachexia. Preventing the loss of appetite that is so often associated with malignancy is a major cause of the nutritional complications found in cancer patients. In some, but not all, an activity program increases intake. If cachectic patients increase activity without parallel increases in intake, tissue wasting rather than tissue gain will occur.

GOAL NP-2:

To increase research on effective dietary and physical activity approaches for the prevention of cancer and increasing survivorship of cancer patients.

Objective NP-2.1:

To evaluate the needs of New Jersey residents with respect to nutrition, physical activity, and cancer and to implement the necessary changes for cancer reduction.

Strategies:

- (NP-2.1.1) Conduct a needs assessment survey of New Jersey residents, including multiple multi-ethnic groups, to assess their current dietary quality, alcohol consumption, use of special diets and dietary supplements in general, their barriers to healthy food choices, their knowledge of the relationship between nutrition, BMI and cancer, physical activity, their attitudes about changing their dietary habits, and what would be useful for them to change

their dietary behavior. This survey could provide baseline data and could be repeated for surveillance purposes.

- (NP-2.1.2) Develop recommendations for future research, improvement of nutrition education strategies, and policy changes based on the results of the survey and the nutrition interventions.

Objective NP-2.2:

To increase the knowledge of the relationship among physical activity, nutrition, and cancer risk.

Strategies:

- (NP-2.2.1) Promote preclinical and clinical research on dietary substances that can potentially reduce cancer risk, including nutraceuticals/functional foods and nutrient-gene interactions.
- (NP-2.2.2) Promote behavioral research on effective, culturally sensitive approaches for dietary modification and exercise promotion.
- (NP-2.2.3) Promote research on dietary and physical activity practices, including use of dietary supplements, that will increase survival and quality of life of cancer patients.
- (NP-2.2.4) Conduct research in the nutritional, metabolic, and gene-expression abnormalities that result in cancer cachexia.
- (NP-2.2.5) Identify seed money or pilot grant to support new research in this area. The successful pilot projects will facilitate obtaining other grants from governmental and private funding agencies.

CANCER SURVIVORSHIP AND NUTRITION/PHYSICAL ACTIVITY

Proper nutrition and appropriate levels of physical activity are likely important to the optimal efficacy of cancer treatment regimens and may reduce the chances of disease recurrence. Dr. Harmon J. Eyre recently stated in the *American Cancer Society Journal CA: A Cancer Journal for Clinicians* that: “Unfortunately, although we currently know a great deal about nutrition and physical activity as they influence cancer

incidence, much less is known about how they affect cancer recurrence and prognosis” (19).

Cancer patients and survivors are intensely interested in nutrition and complementary and alternative treatment regimens. Studies clearly demonstrate that they practice these treatments, often without the knowledge of their physicians and often without sufficient information to support their usefulness or safety (20;21).

Currently every year over 1.2 million people are diagnosed with cancer in the U.S. and there are about 9 million survivors (3). Modern oncologic medical care strives to cure cancer or at the very least to transform it into a chronic disease, e.g., to extend the meaningful survival of those afflicted with cancer. Success on either front will increase the numbers of survivors.

Therefore, it is necessary for patients undergoing cancer treatment and cancer survivors to

have access to solid evidenced-based information on dietary habits and physical activity that will permit optimal health and well-being. Cancer patients and survivors should be able to obtain this information and to avail themselves of appropriate professional advice and services. Access should be equivalent regardless of socioeconomic or education level. Finally, to generate this information more research into the impact of dietary habits, nutrition, and physical activity on cancer survivorship is necessary.

GOAL NP-3:

To assure proper nutritional care for cancer patients.

Objective NP-3.1:

To encourage health care professionals to use nutrition guidelines for cancer patients/survivors during and after cancer treatment.

Strategy:

- (NP-3.1.1) Establish and then promote practice guidelines targeted to healthcare professionals relating to nutritional care for cancer patients.

Objective NP-3.2:

To provide cancer patients/survivors information about proper nutrition and physical activity during and after treatment.

Strategies:

- (NP-3.2.1) Assure that each cancer patient meets with a Registered dietitian *before* and during cancer treatment to provide education concerning nutrition and physical activity and cancer treatment.
- (NP-3.2.2) Lobby for reimbursement coverage for Medical Nutrition Therapy.
- (NP-3.2.3) Provide specific assistance to those New Jersey residents who are receiving/or have received cancer treatment and are currently battling a nutritional problem.

Principal Change Agents: The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society:

Cancer Institute of New Jersey: NP-1.2.2; NP-1.4.1; NP-2.1.1; NP-2.1.2; NP-2.2.1; NP-2.2.2; NP-2.2.3; NP-2.2.4

New Jersey Department of Health and Senior Services: NP-1.1.1; NP-1.1.2; NP-1.1.3; NP-1.1.6; NP-1.2.1; NP-1.2.2; NP-1.2.3; NP-1.3.1; NP-1.4.1; NP-2.1.1; NP-2.1.2; NP-3.1.1; NP-3.2.1; NP-3.2.3

Rutgers, the State University of New Jersey: NP-1.1.2; NP-1.1.4; NP-1.1.5; NP-1.2.2; NP-1.3.1; NP-1.4.1; NP-2.1.1; NP-2.1.2

University of Medicine and Dentistry of New Jersey, Center for the Study of Alternative and Complementary Medicine: NP-2.1.1; NP-2.2.1; NP-2.2.2

University of Medicine and Dentistry of New Jersey, School of Health Related Professions (SHRP) – Dietetics: NP-1.1.1; NP-1.1.4; NP-1.1.5; NP-1.2.2; NP-2.1.1; NP-2.1.2; NP-2.2.1; NP-2.2.2; NP-2.2.3; NP-2.2.4;

NUTRITION/PHYSICAL ACTIVITY

GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Promote health nutrition and physical activity	1.1: Diet education	NP-1.1.1						
		NP-1.1.1						
		NP-1.1.1						
		NP-1.1.4						
		NP-1.1.5						
		NP-1.1.6						
	1.2: Statewide nutrition programs	NP-1.2.1						
		NP-1.2.2						
		NP-1.2.3						
	1.3: Increase physical activity	NP-1.3.1						
2: Increase research	2.1: Evaluate nutrition and physical activity	NP-1.4.1						
		NP-2.1.1						
	2.2: Conduct epidemiologic research	NP-2.1.2						
		NP-2.2.1						
		NP-2.2.2						
		NP-2.2.3						
		NP-2.2.4						
		NP-2.2.5						
3: Assure nutritional care for cancer patients	3.1: Encourage healthcare professional utilization of nutrition guidelines	NP-3.1.1						
	3.2: Educate patient on nutrition guidelines	NP-3.2.1						
		NP-3.2.2						

Target Completion Date

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CHAPTER 5. Childhood Cancer

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CHILDHOOD CANCER

IMPORTANCE OF CHILDHOOD CANCER FOR CANCER PREVENTION AND CONTROL IN NEW JERSEY

Just as children are not “little adults”, childhood cancer is different in many ways from adult cancer. The most common cancers in adults are breast, cervical, colorectal, lung and prostate; children almost never contract any of these. Acute leukemia, central nervous system tumors, neuroblastoma, Wilm’s tumor, and non-Hodgkin’s lymphomas constitute the top five diagnoses under 14 years of age. This is in contrast to Hodgkin’s disease (HD), germ cell tumors, non-Hodgkin’s lymphomas (NHL), melanoma, and soft tissue sarcomas, which are more frequent in youngsters 15 to 19 years of age (Table 1). Many adult cancers have identified risk factors; some adult cancers may be preventable. However, there is very little evidence to indicate the causes of childhood cancer other than cancer genetics.

Although the incidence of cancer in children is much lower than in adults, about 80% of children with cancer will be long-term survivors. It has been estimated that by the year 2010, one in every 250 young adults will be a survivor of childhood cancer. Even though cancers among children represent only about 1% of all cancers, their patterns in the population also merit special attention.

Most adults have already completed their education and are employed (or even retired) before they are diagnosed with cancer; many have already had children. Some children have not even started school before they are diagnosed with cancer; they still have years during which they should be achieving physical and mental maturity. Ideally a child who survives cancer would be able to grow

and develop normally, complete an education, obtain gainful employment, and eventually have children. However, ongoing aggressive treatment with chemotherapy (and sometimes radiation) that improves the probability of survival can also have profound effects on a child who is still growing. For these reasons the Childhood Cancer Subcommittee in contributing to this *Plan* has been challenged to develop solutions for the children with cancer in New Jersey.

Childhood Cancer in New Jersey. Cancer in children and young adults is relatively rare. An estimated 9,100 new cases are expected to occur among children aged 0-14 in 2002, compared to 1,284,900 adults (1). For the period 1979-1995 in New Jersey, the childhood cancer incidence is slightly higher in New Jersey children compared to U.S. children. In New Jersey, the total childhood cancer rate among boys was slightly higher than among girls, mirroring U.S. rates. The incidence of cancer among white children in New Jersey was higher than the corresponding rate for the U.S., but among black children in New Jersey was slightly lower than the U.S. rate (2).

Mortality rates for childhood cancer in the U.S. and New Jersey have declined since the 1970’s (2), representing a nearly 46% decline in mortality in New Jersey alone. The largest declines in mortality have occurred for Hodgkin’s lymphoma, soft tissue sarcoma, and leukemia (acute lymphocytic leukemia, in particular). These trends reflect dramatic successes in the treatment of childhood cancer (2). An estimated 1,400 deaths are expected to occur among children aged 0-14 in 2002, about one-third of them from leukemia. Despite its rarity, cancer is the chief cause of death by disease in children between ages 1 and 14 (1).

**Table 1. Incidence of most common cancers
in 0 to 14 year olds and 15 to 19 year olds, 1990-1997**

TOTAL	<15	15 - 19
Total	141.3	206.8
Acute Lymphocytic Leukemia (A.L.L.)	29.3	11.5
A.M.L.	6.6	8.8
Hodgkin's Disease	5.7	34.7
Non-Hodgkin's Lymphoma	8.5	17.1
Central Nervous System	31.8	20.3
Malignant Bone Tumors Osteogenic & Ewing's	7.0	15.8
Rhabdomyosarcoma	5.1	3.6
TOTAL	94	111.8

Rates are per 100,000

*Abstracted from (3)

Age patterns. Incidence patterns for different types of cancer in children vary dramatically by age. For example, lymphoid leukemia incidence increases to a peak before age five and declines thereafter, while acute myeloid (nonlymphocytic) leukemia incidence is constant throughout childhood. The incidence of Hodgkin's lymphoma increases throughout childhood and is highest in adolescence. Neuroblastoma, retinoblastoma, and Wilm's tumor

incidence rates are highest between birth and age one and decline with increasing age (2).

Risk Factors. Overall, the causes of most childhood cancers remain unknown. Many types of pediatric cancers are related to genetic conditions. There also has been considerable research into the effects of environmental contaminants associated with childhood cancer; however direct causation has not been proven (4;5).

The recommendations of the Childhood Cancer Subcommittee are summarized below for the following six topic areas in priority order:

- Adolescent and Young Adult Treatment
- Secondary Malignancies
- Pain and Palliative Care
- Family Support
- Education
- Advocacy

GOALS, OBJECTIVES AND STRATEGIES

Overall Goal: To enhance the quality of life of the child, adolescent, and/or young adult patient with cancer from diagnosis through treatment to survivorship across the life span.

ADOLESCENT AND YOUNG ADULT TREATMENT

Treatment. Cancer survival in children under 14 is a great success story of the 20th century. In the 1960s, the five-year survival rate for a child diagnosed with cancer

was 28%. By the 1990s this had risen to over 75%. The greatest success was witnessed in acute lymphoblastic leukemia, a virtually incurable disease in the 1960s with a median survival of six months. Today, more than 75% of the children are cured.

Table 2. Five years survival rates in 15 to 19 year olds of selected diagnoses

Time Period	1975-84 (%)	1985-94 (%)
A.L.L.	35	51
A.M.L.	22	42
Hodgkin's	88	90
N.H.L.	56	69
Rhabdo	40	45
Osteo	49	59
Ewing's	36	56

*Abstracted from (7)

As may be seen from Table 2, there have been substantial gains in survival in the 15- to 19-year age group from an earlier period (1975-1984) to the late 1990s. However, this gain lagged behind the significant improvements seen in the younger age group. In 1975 the older group had a survival rate of 64% versus 55% for children under 15. In the 1990s this increased to 76% and 75% for the respective groups. This shows relatively greater improvement in the younger age group. In fact the younger group is approaching an overall survival rate of 85%. This may be attributable to the following:

- Over 95% of the children under 15 are being treated at pediatric cancer centers, and over 60% are treated on national clinical trials. There has been a direct correlation between participation in national protocols and being treated at pediatric cancer centers and the incremental rise in cure rates.
- Only 10% of 15 to 19-year-olds are entered into clinical trials.
- The biology of the disease in the older group may be different.

However, it can be argued that results for the older group may improve through their participation in national clinical trials. The evidence for this is seen in the case of T-cell acute lymphocytic leukemia, which is common in young adults. The Children's Oncology Group with their protocol has demonstrated survival advantage with intensive therapy, and T-cell leukemia is no longer considered a poor prognostic criteria.

- The mortality burden is a function of survival and incidence.
- One example of this are acute leukemias, which constitute only 11% of all cancers in 15- to 19-year-olds as compared to 35% in children under 15 years. The survival rate, on the other hand, is 46% versus 75%.
- Over 80% of mortality in the older group is attributed to four malignancies: sarcomas, leukemias, central nervous system, and germ cell tumors.
- There has been a substantial gain among the younger group in the above diagnoses treated with intensive multimodal therapy. Children's Oncology Group in fact extends the age to 30 years for certain diagnoses, e.g., rhabdomyosarcoma, Ewing's tumor, etc.

To investigate the differences between childhood cancer in ages 0-14 and childhood cancer in ages 15-19, the Childhood Cancer Subcommittee suggests that more clinical research should investigate cancer up to age 21.

Psychosocial support. “The greatest difference in the management of adolescents and young adults is in supportive care, particularly psychosocial care” (3). Every adult can identify with adolescence. It is the most difficult period of any one's life without the added “curse” of cancer. Medical management (chemotherapy) is only a small portion of the overall supportive care the youngster deserves not only to achieve a cure, but also to become a productive citizen. This requires a multi-disciplinary team approach, perhaps best accomplished at a pediatric oncology center for this group of young adults.

Cancer in adolescents and young adults is more common than in younger children. However, the survival rate has not kept pace in certain types of cancers seen in both groups. This may be due to relative lack of participation by the older group in national clinical trials (6-14).

GOAL CC-1:

To improve care for adolescents and young adults.

Objective CC-1.1:

To educate healthcare providers about the availability of existing clinical research protocols and the referral of young adults up to the age of 21 to pediatric oncology centers.

Strategy:

- (CC-1.1.1) Conduct a pilot study to validate the existing research and assess any difference in cancer survival based on treatment regime between adult treatment centers and pediatric treatment centers.

Objective CC-1.2:

To identify how the current psychosocial needs are met for this group of patients.

Strategies:

- (CC-1.2.1) Develop and distribute a questionnaire on cancer services for adolescents and young adults to the participating centers (oncologists, social workers, community agencies involved and a group of randomly selected patients at the centers).
- (CC-1.2.2) Utilize results of the survey on cancer services for adolescents and young adults to identify gaps in service and provide feedback to participants in order to address unmet needs.

SECONDARY MALIGNANCIES

Survivors of childhood cancer represent a growing population. This pool is expanding because of the increase in survival and cure rates. Over the past three decades, the incidence of childhood malignancies has increased slightly from 12 to 14 per 100,000 population of under-15-year-olds. The mortality rate has decreased from 6 to 3 per 100,000 (15) and the five-year survival is approaching 80% (16). This creates a pool of survivors, which currently is estimated at 1 in 900 individuals between 15 and 45 years old. It is projected that this number may reach 1 in 250 young to mid-aged adults by 2010 (17;18).

This population will challenge their healthcare providers to address the medical, emotional, and societal sequelae of cure. One

question already being asked on behalf of the survivor is: What is the mortality rate of the survivor population compared to that of the general public?

Several studies have addressed this issue and some degree of consensus has been reached. Of those that die having been off therapy greater than five years but in most cases less than 15 years, the primary cause of death has been recurrence of the primary disease. This has accounted for about 65% of deaths, whereas about 25% occur from issues related to the primary disease and its treatment. Second malignant neoplasms (SMN) are the most common cause in this latter category (16;19-21).

Overall approximately 10% of survivors may die in the first several decades after therapy. SMN accounted in one study for 6.8% of the

deaths representing 20 of 2,319 survivors originally followed or 0.86% of the survivor population of that study (19).

The cumulative risk of SMN remains unknown, but various studies have put that risk between 1.2% and 12% at 20 years off therapy. A long prospective longitudinal study of our pediatric survivors is needed to ascertain whether known adult type malignancies will occur at a younger age and with increased frequency in the survivor population.

There is an ample body of literature suggesting SMN as a risk to the childhood cancer survivor. Age at diagnosis, gender, primary cancer, type/dose therapy received, and genetic predisposition have an impact upon the risk of SMN.

One of the most comprehensive reports of SMN comes from the Childhood Cancer Survivor Study (CCSS) looking at a cohort of 13,581 children diagnosed with the common childhood cancers prior to age 21 years between January 1, 1970 and December 31, 1986, and followed at 25 selected institutions. The cohort was five years or greater survivors. The median age was 23 years (range 8 to 47 years). There were a total of 140,792 person-years of follow-up with median time of 15.4 years (range 6.4 – 28.7 years). Excluded were those who died of SMN before five years off therapy and those with a diagnosis of retinoblastoma.

For the most part results supported previous studies. Three hundred fourteen SMNs were found in 298 individuals. Twenty years after the childhood cancer diagnosis, the cumulative estimated SMN incidence was 3.2%. Those with a primary diagnosis of Hodgkin's Disease had the highest cumulative incidence at 20 years: 7.6%. The most frequent SMNs were breast (n=60), thyroid

(n=43), and central nervous system (n=36) (22).

Second malignant neoplasms are rare events, but they exact a considerable emotional toll on young adult survivors and their families. All primary care physicians who treat survivors of childhood cancer should have an increased index of suspicion for a second malignant neoplasm based upon the survivor's individual risk profile. With identification of specific high-risk factors among the survivors, surveillance is more focused, providing an opportunity for early prevention and treatment.

Subsets of patients in numerous publications have been identified as being at higher risk of SMN. These include:

- Those exposed to radiation: bone/soft tissue sarcoma, central nervous system, breast, and thyroid.
- Those exposed to specific chemo-therapeutic agents: alkylators, epipodophyllotoxins, anthracyclines (CCSS).
- Genetic predisposition: those with bilateral retinoblastoma (or unilateral hereditary retinoblastoma), Li-Fraumeni syndrome, neurofibromatosis, familial adenomatous polyposis, hereditary nonpolyposis colorectal cancer, multiple endocrine neoplasias, basal nevus syndrome, ataxia telangiectasia, Bloom's syndrome, and Fanconi's syndrome.
- SMN is highest among those with Hodgkin's Disease as primary diagnosis.
- Female gender ($p < .001$ CCSS).
- Childhood cancer diagnosis at younger age ($p < .001$ CCSS).
- Female children with radiation therapy to the chest and possibly radiation therapy to the abdomen if less than 7 years old should be surveyed for breast cancer.

The CCSS stated: “At the time of analysis 91.9% of the cohort members who had not developed an SMN were alive compared with 59.4% of cohort members who had developed an SMN.” The analysis was done on data collected as of January 1, 2000. This finding emphasizes the need for surveillance to possibly detect and intervene early in the occurrence of second malignant neoplasms (22).

The list of high-index suspicion subsets should be inclusive to single out those survivors needing special consideration for increased surveillance by primary care providers.

The issue statement would refer to surveillance and possibly early detection and diagnosis of SMN. Subsets relative to one type of SMN can be developed with screening options.

GOAL CC-2:

To reduce incidence of and mortality from secondary malignancies.

Objective NP-2.1:

To identify guidelines for screening of individuals who have been diagnosed with childhood cancer.

Strategies:

- (CC-2.1.1) Conduct a literature survey and interview experts in order to compile guidelines for screening of childhood cancer survivors.
- (CC-2.1.2) Convene a consensus conference and produce a report that will contain a consensus statement and the development of screening guidelines for childhood cancer survivors where needed.
- (CC-2.1.3) Disseminate screening guidelines for childhood cancer survivors through the development of a publication to be distributed to all healthcare providers and patients.

Objective CC-2.2:

To disseminate healthy lifestyle information to childhood cancer survivors to reduce environmental factors contributing to second malignant neoplasms.

Strategy:

- (CC-2.2.1) Develop media campaign and brochures to educate childhood cancer survivors on environmental risk factors for second malignant neoplasms.

PAIN AND PALLIATIVE CARE

Approximately 12,400 children under 21 are diagnosed each year with cancer. The majority of these children are expected to survive, with five-year survival rates now approaching 80%. However, over 2,000 children each year still die as a result of cancer, which is the second leading cause of childhood mortality, following accidental deaths and homicides. Therefore, not only are these children and the families of these children faced with the prospect of having a serious disease with treatment that can result in life-threatening or life-altering complications, but they must also come to terms with the possibility that the child might die. As a consequence, it has been advocated that all children with life-threatening medical conditions regardless of the prognosis, including cancer, should be involved in a palliative care program early in the diagnosis, with the special needs of children being addressed.

There is some disagreement over the term *palliative care*, since this term is often associated with terminal illness where there is no hope for survival and where the treatment shifts from curative intent to providing comfort for the last few weeks of life. However, palliative care has in recent years undergone a paradigm shift (see Palliation Chapter 3). As recently as 1987, when palliative care was recognized as a medical specialty, the focus was on patients whose prognosis was poor and was limited to maximizing quality of life at the end of life. A more global approach was suggested by the World Health Organization in 1990: "...

control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment." More recently in 2001 a white paper produced by the Children's International Project on Palliative/Hospice Services stated: "Palliative care is the science and art of lessening physical, psychosocial, emotional, and existential suffering. Palliative care can benefit patients and families whether the overall goals of care are to cure, prolong life, maximize the quality of life that remains or ease the pain of bereavement. Thus, palliative care may be provided concurrently with, or as an alternative to life sustaining medical intervention...A palliative care knowledge base exists that can substantially improve the experience of children living with life threatening conditions. However, because this knowledge is not widely taught in health professors' training programs, and in part because it is care that is currently unpaid, pediatric palliative care is not widely available." Clearly by adopting this broader concept, palliative care would be introduced at the time of diagnosis.

Beyond addressing the emotional impact of the cancer diagnosis, implicit in this broader concept of palliative care is the intent to deal with multiple complications related to both the underlying disease and the treatment of the cancer. These symptoms include diarrhea and constipation, nausea and vomiting, fatigue, anorexia, dyspnea, and pain. Pain

continues to be of paramount importance in that it is very often the prevalent symptom from the time of diagnosis and throughout treatment. Pain is multi-factorial; it can be related to the cancer itself, the invasive procedures used to diagnose or treat the cancer, or the therapies used such as surgery, chemotherapy, or radiation. It is also very often the most important issue for the child dying of cancer. In one recent study by the Dana Farber Cancer Center, published in the *New England Journal of Medicine* in 2000, 80% of children dying of cancer experienced significant pain. Unfortunately, according to the parents' perceptions, only 20% of these

children had their pain adequately managed. So, while we have the tools necessary to alleviate a great deal of the suffering associated with cancer pain, all too often these tools are inadequately utilized. As in adults, there appear to be significant barriers to the successful treatment of children with cancer-related pain during all phases of the disease process. These barriers are related to inadequate knowledge by health professionals regarding the proper use and the side effects of analgesics, especially narcotics, as well as misunderstanding by patients and their families (23-29).

GOAL CC-3:

To increase the awareness of healthcare professionals, patients, and families on the use of palliative care strategies in the child with cancer. Pain management can be used as an example of how these strategies can be implemented successfully.

Objective CC-3.1:

To educate healthcare professionals, childhood cancer patients, and families about palliative care strategies in the management of cancer-related symptoms including pain.

Strategy:

- (CC-3.1.1) Develop a statewide educational forum for providers, childhood cancer patients, and family members that will include palliative care and pain management strategies.

FAMILY SUPPORT

Every pediatric oncology medical treatment program in New Jersey should provide emotional support services to a patient's siblings and parents as well as to the patient.

The literature documents the negative impact on siblings and parents when a child is

diagnosed with cancer. Much of the literature has focused on posttraumatic stress in relation to the family after a childhood cancer diagnosis, with an indication of parental symptoms consistent with Post-Traumatic Stress Disorder (PTSD) (e.g., avoidance, intrusive thoughts, hypervigilance, etc.). Kazak et al. completed a study comparing symptoms of anxiety and posttraumatic stress in parents of children and adolescents

diagnosed with cancer with a control group of parents whose children and adolescents were not diagnosed with a chronic illness (30). The study, involving 130 cancer survivors and their parents with a comparison group of 155 children and their parents, included five measures of anxiety and stress, with two of the measures involving family functioning and social support. The results of the study revealed significantly higher levels of posttraumatic stress symptoms in parents of children diagnosed with cancer as compared to those parents whose children have not been diagnosed with a chronic illness. Moreover, study findings linked parents' perceived higher levels of social support to fewer posttraumatic stress symptoms. This confirms the notion that quality of life of survivors, siblings, and parents can be improved by addressing impact at time of treatment and subsequently through psychosocial support at treatment centers.

The services of the child life/creative arts specialist are essential to meeting the goals of providing emotional support, age-appropriate explanations of the diagnosis and treatment, preparation for procedures, and the modalities with which the child may express his or her anxieties, frustrations, and anger over interruption of "normal" life. These modalities include the use of art, music, dance, and play, with which the therapist seeks to engage the child in counseling and comfort consistent with their developmental age. The effects of such interventions are often beneficial to the family's coping, to siblings' well being and interactions, and allow for more time- and cost-efficient delivery of healthcare.

The Academy of Pediatrics has recognized the importance of child-life services and recommended that such services should not be withheld because of financial constraints. Child-life services represent an important foundation for providing a better quality of life for the youngster during treatment and help ensure that child survivors meet the emotional and social milestones of their peers.

Literature supports the nature and severity of stressors, reactions, and coping strategies that point toward possible interventions. Stuber and Kazak (31) found that clinical interventions during treatment reduced not only the family's immediate stress levels, but continue to provide emotional benefits after acute care. In keeping with current research, Stuber and Kazak recommended reducing family stress levels by assisting the family in "developing a realistic but hopeful understanding of life threat and reducing the perception of treatment intensity" (31). In addition, the study recommended "adequate and developmentally appropriate explanations and preparations for procedures and treatment, and careful control of pain and nausea." Interventions can be specific in terms of types of professionals used (psychologists, social workers, creative life therapists) and ratio of patients to professionals recommended/required. Delivery of services can also be measured in terms of groups/programs offered at a given institution. Studies document the poor quality of life related to sibling/parent anxiety, grief (losses, not only death), and perseverance over problems lasting over time. The literature also compares parent populations only by child's disease severity or prognoses, not by geography, ethnicity, etc.

GOAL CC-4:

To foster the psychosocial health of the child with cancer and the family.

Objective 4.1:

To maximize the quality of life of the child with cancer and the family.

Strategies:

- (CC-4.1.1) Conduct a statewide survey to identify existing psychosocial support mechanisms at each pediatric oncology treatment center.
- (CC-4.1.2) Identify community resources for psychosocial support for children with cancer and their families in conjunction with a capacity and needs assessment.

Objective 4.2:

To assess the psychosocial mechanisms utilized in treatment centers and the community.

Strategies:

- (CC-4.2.1) Conduct a literature review to investigate psychosocial standards of care.
- (CC-4.2.2) Collaborate on a consensus statement for psychosocial standards of care with key stakeholders.

Objective 4.3:

To ensure that appropriate and continuous psychosocial support is provided for every child with cancer and the child's family.

Strategies:

- (CC-4.3.1) Through a legislative initiative, require the assignment of a professional caseworker to provide *ongoing* psychosocial assessment and intervention of every child and his/her family as per standard of care.
- (CC-4.3.2) Research existing reimbursement policies and mechanisms to evaluate current trends in non-reimbursement for psychosocial services.
- (CC-4.3.3) Partner with the insurance industry to further reimbursement of psychosocial services on an *ongoing* outpatient basis.

EDUCATION

Each year approximately 7,500 U.S. children younger than the age 15 are diagnosed with cancer; of 80% are expected to be cured of their disease. Currently it is estimated that 1 in 900 persons ages 15 to 45, are childhood cancer survivors in the U.S. In the year 2010, the statistics are expected to increase to as many as 1 in every 250 persons. According to estimates in the U.S. college-age population this would mean that approximately 67,000 individuals between the age of 18 to 21 would be childhood cancer survivors. By these estimates childhood cancer survivors would comprise a large portion of the population. Some reports suggest that up to 50% of survivors are likely to have late effects of their cancer therapy, which may lead to significant disabilities that alter quality of life. This brings to light the need to screen childhood cancer survivors for late effects of their past treatment.

Many survivors see their pediatric oncologists, either regularly or on an occasional basis, after completing treatment for the underlying malignancy, so that they can be monitored and screened for late effects of their therapy. Their primary medical care is managed by pediatricians, family practitioners, internists, and nurses. It is extremely important for these

caretakers to be aware of the consequences of survivors' previous treatments for normal tissues and organ systems.

The available literature has well documented late effects of treatment for survivors of childhood cancer, whether surgical, chemotherapy or radiation induced. Adverse effects have been shown to many organ systems, such as CNS, neuroendocrine, ocular, dental, musculoskeletal, cardiovascular, pulmonary, gastrointestinal, hormonal function, fertility, and risks of secondary malignancies.

Central Nervous System: Neurocognitive deficit (difficulty reading, language, verbal and non-verbal memory, arithmetic, receptive and expressive language, decreased speed of mental processing, attention deficit, decreased IQ, behavior problems, poor school attendance, poor hand-eye coordination); leukoencephalopathy (seizures, neurologic impairment); focal necrosis (headaches, nausea, seizures, papilledema, hemiparesis, speech, learning and memory deficits); stroke; blindness; ototoxicity (abnormal speech development, hearing loss); myelitis (paresis, spasticity, altered sensation, loss of sphincter control); peripheral neuropathy (generalized weakness, localized weakness, lack of coordination, tingling and numbness).

Neuroendocrine: Growth hormone deficiency (poor growth/growth retardation); ACTH deficiency (muscular weakness, anorexia, nausea, weight loss, dehydration, hypotension, abdominal pain, increased pigmentation); TRH deficiency (hoarseness, fatigue, weight gain, dry skin, cold intolerance, dry brittle hair, alopecia, constipation, lethargy, poor linear growth, menstrual irregularities, pubertal delay, bradycardia, hypotension); precocious puberty (early growth spurt, false catch-up, premature sexual maturation); gonadotropin deficiency (delayed or absent pubertal development, testicular atrophy, infertility, abnormal menses, estrogen deficiency); hyperprolactinemia (abnormal menses, infertility, galactorrhea, osteopenia, loss of libido, hot flashes, impotency).

Ocular system: Dry, red eyes; tearing; ulcerations; tortuous vessels; pain; decreased visual acuity; cataracts.

Head and neck/dental: Decreased saliva, dental decay, thrush, ulcerations, chronic rhinitis, facial pain, headache, hearing impairment, chronic ear infections, hair loss.

Musculoskeletal: Muscular hypoplasia, spinal abnormalities (scoliosis, kyphosis, etc.), limb length discrepancy, pathological

fracture, osteoporosis, osteonecrosis, osteocartilaginous exostoses, slipped capto-femoral epiphysis.

Cardiovascular: Cardiomyopathy, valvular damage, pericardial damage, coronary artery disease.

Pulmonary: Pulmonary fibrosis.

Gastrointestinal: Enteritis, adhesions, esophageal strictures, fibrosis of small and large intestines, hepatic fibrosis/liver failure.

Thyroid dysfunction: Hypothyroidism, thyroid nodules, hyperthyroidism.

Infertility: Ovarian failure, premature menopause, decreased or absent sperm production, testicular atrophy (3;32).

With the longer life span and increasing numbers of survivors of childhood cancer, it is important to help educate primary care physicians, pediatricians, family practitioners, internists, and nurses on these late effects, the need for screening, and treatment/referral recommendations (3;32; 33).

GOAL CC-5:

To increase awareness of healthcare providers of late effects in childhood cancer.

Objective CC-4.1:

To identify guidelines for screening and management of late effects of childhood cancer.

Strategies:

- (CC-5.1.1) Research and develop guidelines for screening childhood cancer patients previously treated with chemotherapy or radiation therapy.
- (CC-5.1.2) Collate and condense guidelines for referral and/or management recommendations of childhood cancer survivors for primary care physicians.
- (CC-5.1.3) Disseminate guidelines for management of childhood cancer survivors through the development of a public brochure and/or website and/or letter updates for all practitioners. Update as new information becomes available.

GOAL CC-6:

To increase the awareness of neurocognitive deficits in childhood cancer patients.

Objective CC-6.1:

To educate patients and families on neurocognitive deficits in childhood cancer patients post treatment.

Strategy:

- (CC-6.1.1) Develop a statewide educational forum for educators, childhood cancer survivors, and family members that would address the issue of neurocognitive deficit.

ADVOCACY

Advocacy for individual childhood cancer patients and their families should begin at the time of diagnosis. Education and advocacy are inextricably intertwined. Parents who are still in shock after being told their child has cancer must suddenly deal with a multitude of problems. They must learn the unfamiliar skills involved in taking care of their sick child, such as administering medications on schedule and taking care of central venous catheters. They must learn

how to interact with the school system to ensure their child receives an appropriate education and is not penalized for having to miss school. They must also continue to meet the ongoing, day-to-day needs of the patient's siblings. One parent may need to take a leave of absence from work, or even relinquish a job to devote additional time to their sick child.

Legislation passed in the mid-1990s has given patients and their families some new rights regarding education and health insurance.

Parents should learn what Family Medical Leave Act benefits entail in order to obtain a leave of absence from work without penalty.

Education. The various legal protections, programs, and designations available to children with cancer and their families are well described in Keene et al. (33), Weiner et al. (34), and Monaco, et al. (35). For various reasons, some schools and systems are easier to work with than others. Parents may need help negotiating with an individual school system, but the guidelines in these references are reasonably clear and straightforward. A child receiving treatment should be eligible for a number of programs designed to permit continuation of schooling. Because of the late effects of some types of treatment (e.g., cranial irradiation), children may not experience learning difficulties until years after conclusion of treatment. A child who has always managed to do well in grade school by working hard may be unable to handle the additional work required in junior high or high school. Not all child study teams or school psychologists (to say nothing of teachers) are aware of the learning problems children with cancer or survivors of childhood cancer may face.

Employment. Keene et al. (33), Weiner et al. (34), and Monaco, et al. (35) also explain the legal protections and practicalities of employment. The fact is noted, for example, that a potential employer has no right to ask health history questions or to require a physical examination until after a preliminary job offer has been made. The importance of accurate assessment of cancer survivors' abilities and appropriate vocational counseling is also mentioned. It is particularly important that survivors left with neuropsychological problems and/or neurodevelopmental delay be given adequate support, as they are at increased risk of being unable to secure or maintain a job.

Unfortunately, many survivors who have had brain tumors or who have required high doses of cranial irradiation are left with such neurological deficits.

Insurance (during the child's treatment).

Few people are familiar with all the nuances of their health insurance coverage; such knowledge is further complicated by the changes frequently made in these plans requiring prior authorization or lab tests to be performed at designated facilities. Different insurance companies and HMOs vary greatly in their procedures and requirements related to the patient's care.

Insurance (for the cancer survivor). Vann, et al. (36) found that young adult survivors of childhood cancer were "more likely to be denied health insurance than their siblings, with an adjusted odds ratio of 15.1" and "had health insurance policies that excluded care for pre-existing medical conditions more often than their siblings (OR = 5.5)" (36). Now the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA), have improved the situation for cancer survivors and their families. If a parent of a child diagnosed with cancer or a cancer survivor changes jobs, these laws protect them from losing their health insurance. If a family (or patient) does not have insurance in effect at the time of diagnosis, it can still be extremely difficult to obtain insurance. If a young adult who has survived childhood cancer no longer qualifies for coverage under his parent's insurance, he may find it nearly impossible to obtain health insurance coverage without a substantial waiting period (usually a year) for coverage of pre-existing conditions. Private individual insurance may be prohibitively expensive; an insurer cannot refuse to issue a policy, but the premiums may be very high because of an individual's health history. The guide by

Keene et al. advises the cancer survivor not to look for a job in a small company: "The easiest way to get insurance is for you or your spouse to work for a large corporation or government agency that provides a group health insurance policy. The larger the pool of employees, the less likely you are to be rejected from health coverage..." (33).

Despite some progress, cancer survivors inarguably have more difficulty obtaining insurance than their peers, and this situation is not likely to improve. Within the past two to three years, the results of several studies of five-year (and more) survivors of childhood cancer have reported the incidence of second malignancies in these patients and an increased late mortality experience, e.g., deaths due to late effects of chemotherapy and radiation, not just to relapsed cancer or secondary malignancies (16). A program to follow survivors of childhood cancer will use the results of these studies to plan for screening for cardiac or pulmonary dysfunction, as well as second malignancies (22). Will insurance pay for these tests? Will an insurer consent to enroll a new client with these documented additional risks?

An increasing number of "cancer genes" have also been identified. Li's exemplary discussion of the dilemmas posed by detecting one of these genes in an individual (and in a family) includes the RB1 retinoblastoma gene (37). Fortunately it is very rare: an infant who inherits the RB1 gene has a 90% likelihood of developing retinoblastoma, usually in both eyes. The child who survives hereditary retinoblastoma has an increasing chance of subsequently developing another cancer; a 50% likelihood of developing another cancer by age 50 years (compared to a 5% risk of a second cancer in a patient with sporadic retinoblastoma). As each new cancer gene is identified, the dual opportunity appears. The physician can

potentially identify a patient who should have earlier and more frequent screening for particular cancers, thereby increasing the probability of early detection (and, hopefully, cure) of cancer. Yet the insurer can also potentially identify a high-risk participant. Although legislation has been developed to protect the privacy of patients, and various attempts have been made to prevent insurance companies from obtaining the results of tests for cancer genes, legal protections need to be developed to allow physicians to order appropriate screening for at-risk individuals without breaking confidentiality requirements.

Oeffinger et al. sent a brief questionnaire to the 219 institutional members of the Children's Cancer Group and Pediatric Oncology Group; 182 members responded (38;39). Only 80 of the institutions who responded had long-term follow-up clinics. Although 44% had a mechanism for following up adult survivors, only 15% of the programs had established a formal data base for young adults. The institutions were asked which of several factors interfered with long-term cancer-related follow-up for young adults, and responses included patients' uncertainty about need for follow-up (76%), patients' unwillingness to come (66%), and lack of insurance (63%). The same group found that among the 99 patients participating in the long-term follow-up program, 69% had at least one late effect (36% had two or more) and 30% had a CTCv2 Grade 3 or 4 late effect (Common Toxicity Criteria, version 2, of NCI). Sklar reported that of 650 survivors followed in the Long Term Follow Up Clinic at Memorial Sloan-Kettering Cancer Center, "the most common sequelae are endocrine complications, which are seen in 40% of the patients" (40). Strickland et al. reported that among those surviving patients transfused between 1961 and March 1992, 66% were found to be infected with Hepatitis C (41).

With HMOs dropping Medicare populations and then Medicaid populations because of the expense involved in their care, protecting these “predictably expensive” childhood cancer patients and survivors will be a difficult undertaking.

The importance of educating cancer survivors cannot be overemphasized. Blacklay et al. describe providing an information booklet to 50 adult survivors of cancer in childhood (42). The booklet for survivors over the age of 14 years included “information about treatment of cancer, general advice about a healthy lifestyle, the rationale for long-term follow-up, and information about employment and life insurance problems.” A small survey was then administered to these patients to evaluate whether the booklet had been

effective. Over three-quarters of the patients reported they had learned new information from the booklet and better understood the risks of sunbathing and the importance of follow-up.

Perhaps the simplest solution to the problems of educating patients and families about the complications and possible late effects of the disease, as well as about problems likely to be encountered in education, employment, and insurance, would be to distribute a copy of the book by Keene, Hobbie, and Ruccione (33). It is remarkably comprehensive, practical, and easy to read. Published in 2000, it includes numerous helpful references and websites, as well as email addresses of two of the authors to assist patients in locating follow-up clinics.

GOAL CC-7:

To increase advocacy for childhood cancer, especially on issues related to long-term survivorship, education, employment, and insurance coverage.

Objective CC-7.1:

To educate legislators and key decision-makers about issues in childhood cancer.

Strategy:

- (CC-7.1.1) Investigate the establishment of a grassroots childhood survivorship organization.
- (CC-7.1.2) Develop and fund an advocacy campaign on childhood cancer concerns targeting legislators.

Objective CC-7.2:

To educate childhood cancer survivors and families about issues in childhood cancer.

Strategies:

- (CC-7.2.1) Investigate established models for teaching childhood cancer advocacy to the lay community.
- (CC-7.2.2) Host a statewide conference for parents and childhood cancer survivors utilizing the model with demonstrated effectiveness for teaching advocacy.
- (CC-7.2.3) Collaborate with multi-disciplinary organizations, e.g., American Cancer Society, New Jersey Education Association, New Jersey State School Nurses Association, to re-institute educator conferences on childhood cancer survivorship issues.

Objective CC-7.3:

To educate insurance companies about issues in childhood cancer.

Strategy:

- (CC-7.3.1) Utilize the grassroots childhood cancer survivorship organization to educate insurance companies on the cost effectiveness of surveillance.

Principal Change Agents: The following organizations will contribute to the implementation of strategies shown. This list is not mutually exclusive.

American Cancer Society

New Jersey Department of Health and Senior Services: CC-2.1.3; CC-5.1.3

New Jersey Pediatric Hematology Oncology Network: CC-1.1.1; CC-1.2.1; CC-1.2.2; CC-2.1.1; CC-2.1.2; CC-2.1.3; CC-2.2.1; CC-3.1.1; CC-4.1.1; CC-4.2.1; CC-4.2.2; CC-5.1.1; CC-5.1.2; CC-5.1.3; CC-7.1.1; CC-7.2.1; CC-7.2.2; CC-7.2.3; CC-7.3.1

Tomorrows Children's Institute: CC-6.1.1

CHILDHOOD CANCER								
GOAL	OBJECTIVE	STRATEGY	2003	2004	2005	2006	2007	On-going
1: Adolescent and young adult treatment	1.1: Improve care	CC-1.1.1						
	1.2: Address psychosocial needs	CC-1.2.1						
		CC-1.2.2						
2: Reduce incidence and mortality from secondary malignancies	2.1: Identify guidelines for screening	CC-2.1.1						
		CC-2.1.2						
		CC-2.1.3						
	2.2: Disseminate healthy lifestyle information to survivors	CC-2.2.1						
3: Palliative care awareness	3.1: Provide palliative care education	CC-3.1.1						
4: Foster psychosocial health	4.1: Maximize quality of life	CC-4.1.1						
		CC-4.1.2						
	4.2: Assess psychosocial care	CC-4.2.1						
		CC-4.2.2						
	4.3: Ensure continuous psychosocial support	CC-4.3.1						
		CC-4.3.2						
		CC-4.3.3						
5: Educate healthcare providers of late effects	5.1: Identify guidelines for screening and management	CC-5.1.1						
		CC-5.1.2						
		CC-5.1.3						
6: Neurocognitive deficits	6.1: Provide post treatment education	CC-6.1.1						
7: Advocacy	7.1: Educate legislators/key decision-makers	CC-7.1.1						
		CC-7.1.2						
	7.2: Educate survivors and families	CC-7.2.1						
		CC-7.2.2						
		CC-7.2.3						
	7.3: Educate insurance companies	CC-7.3.1						

Target Completion Date

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